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Jannike Dyb Oksavik

"What matters to you?"  
Goal-oriented, integrated care  
for older patients with  
multimorbidity  
- a qualitative study

**NTNU**  
Norwegian University of Science and Technology  
Thesis for the Degree of  
Philosophiae Doctor  
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Department of Health Sciences Ålesund



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**Norsk tittel: «Hva er viktig for deg?» Målorientert omsorg i helhetlige pasientforløp for eldre pasienter med multisykdom – en kvalitativ studie**

Et helsepolitisk mål i flere land er å øke pasientmedvirkning slik at tjenestene sentreres mot det som er viktig for pasientene. Ved sykdomsepisoder trenger mange eldre pasienter med flere kroniske sykdommer opphold i sykehus og/eller i korttidsavdelinger og deretter eventuelt i hjemmet. Eldre pasienter har tidligere i liten grad deltatt i beslutninger om dette forløpet. Norske kommuner innfører at pasientene deltar i å utforme eget pasientforløp ved en samtale basert på spørsmålet «Hva er viktig for deg?».

Forskningsspørsmålene i avhandlingen er hvordan pasientmedvirkning i «Hva er viktig for deg?»-samtalen forstås på ulike nivå av helsetjenesten, hvilke tilnærminger helsepersonell tar for å involvere pasientene, samt hvordan pasientmedvirkning utspiller seg i «Hva er viktig for deg?»-samtalen og erfares av pasienter.

Resultatene i avhandlingen er at begrunnelsene for hvorfor pasientene skulle medvirke var knyttet til prinsippet om individualisering på nasjonalt nivå av helsetjenestene, og skiftet til standardisering på praksisnivå (artikkel 1). Helsepersonell erfarte at de tok fire ulike tilnærminger når de satte mål for pasientforløpet sammen med pasientene med utgangspunkt i spørsmålet «Hva er viktig for deg?»: Motivere for målsetting, sette mål på vegne av pasienten, forhandle på mål og spesifisere mål. Helsepersonell tok disse tilnærmingene for å dele ansvaret for målsetting med pasientene (artikkel 2). I «Hva er viktig for deg?»-samtalen opplevde noen pasienter uforutsigbarhet, knyttet til eget sykdomsforløp, hvilke helsetjenester de ville motta og hvordan de ville kunne bidra i egen rehabiliteringsprosess. Uforutsigbarheten var forbundet med graden av pasientmedvirkning i møtene, og hvor lang frem i tid pasienten ønsket å planlegge (artikkel 3).

Resultatene er basert på analyse av dokumenter som stortingsmeldingen «Leve hele livet En kvalitetsreform for eldre», en klinisk veileder, og skriftlige verktøy for helsepersonell. Helsepersonell delte sine erfaringer i fire fokusgruppeintervju. Videre ble «Hva er viktig for

deg?»-samtalen undersøkt gjennom observasjon av ti møter mellom helsepersonell og pasient, med individuelle intervju med pasientene etter møtet. Studien inkluderer fire kommuner. Analysemetodene er innholdsanalyse, grounded theory og stegvis deduktiv-induksjon.

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## List of papers

### **Paper 1**

Oksavik, Jannike Dyb, Turid Aarseth, Marit Solbjør, Ralf Kirchhoff. 2021. 'What matters to you?': normative integration of an intervention to promote participation of older patients with multi-morbidity – a qualitative case study. *BMC Health Services Research*, 21(117). doi:10.1186/s12913-021-06106-y

### **Paper 2**

Oksavik, Jannike Dyb, Ralf Kirchhoff, Maren Kristine Raknes Sogstad, Marit Solbjør. 2020. Sharing responsibility: municipal health professionals' approaches to goal setting with older patients with multi-morbidity – a grounded theory study. *BMC Health Services Research*, 20(141). doi:10.1186/s12913-020-4983-3

### **Paper 3**

Oksavik Jannike Dyb, Marit Solbjør, Ralf Kirchhoff, Maren Kristine Raknes Sogstad. 2021. Games of uncertainty: the participation of older patients with multimorbidity in care planning meetings – a qualitative study. *BMC Geriatrics*, 21(242). doi:10.1186/s12877-021-02184-z

## Abbreviations

WHO: The World Health Organization

WMTY: “What matters to you?”

OECD: Organization for Economic Co-operation and Development

## Definitions of key concepts

**Collaborative goal setting** is a process for agreeing on a health-related goal (Vermunt et al. 2017).

**Goal-oriented care** can be defined as care that seeks “to explore patients’ goals, preferences, and needs and to center care and decision-making around these” (Vermunt 2018, 15).

**Health professionals** involved in integrated care pathways for patients with multimorbidity often form a multidisciplinary team (Leijten et al. 2018). This thesis considers the work of nurses, auxiliary nurses, physicians, physiotherapists, and occupational therapists. Case managers who work in offices where health services are allocated are also involved in care planning and therefore are included here.

**Integrated care** involves “structured efforts to provide coordinated, pro-active, person-centered, multidisciplinary care by two or more well-communicating and collaborating care providers, either within or across services” (Leijten et al. 2018, 13).

**Integrated care pathways** are a tool to structure or design care processes and improve them within the patient-centered care concept (Vanhaecht et al. 2010, 118).

**Interpersonal integration** is the extent of collaboration or teamwork among health professionals, nonprofessional caregivers, and patients. Patients’ values and preferences are elicited and included in care planning, and health service delivery forms a single or coherent process (Singer et al. 2020, 199 and 201).

**Intervention** is “an act performed for, with or on behalf of a person or population whose purpose is to assess, improve, maintain, promote, or modify health, functioning or health conditions” (WHO 2021). In this thesis, the term “intervention” refers to care planning with patients, specifically the WMTY intervention.

**Multimorbidity** means that an individual has two or more chronic diseases (Xu, Mishra and Jones 2017).

**Normative integration** is “the development and maintenance of a common frame of reference (i.e., shared mission, vision, values and culture) between organizations, professional groups and individuals” (Valentijn et al. 2013, 8). In this thesis, normative integration is limited to the normative justifications for patient participation, between macro-, meso-, and micro levels of health services.

**Patient participation** in care planning means that patients participate in formulating individual goals for service delivery (Vermunt 2018, 15).

**Person-centered care** means “that individuals’ values and preferences are elicited and, once expressed, guide all aspects of their health care, supporting their realistic health and life goals” (American Geriatrics Society 2016, 16).

**Primary health care** is in Norway delivered by the municipalities (Saunes, Karinkolos and Sagan 2020). This thesis considers services for older patients, including different kinds of rehabilitation wards (intermediate care units and short-term wards at nursing homes), which utilize multidisciplinary teams. Home care services include nurses and auxiliary nurses who provide nursing procedures and assistance (e.g., personal hygiene and medication). Physiotherapists and occupational therapists also make home visits, for reablement (time-limited rehabilitation) and delivery of aids, respectively.

**“What matters to you?”** is a question that health professionals ask patients as a basis for a conversation about patients’ values, preferences, and needs (i.e., patient goals). WMTY is used in care planning: the WMTY intervention (Norwegian Directorate of Health 2018a).

## Summary

Even though patient participation has been upheld as an ideal in health policy for decades, older patients have participated only marginally in the formulation of their healthcare. Older patients with multimorbidity (that is, two or more chronic conditions) have complex needs for health and care services. The goals for the services that patients receive are often not unified, whether we are talking about alignment and integration between different service levels or between different health professionals and their respective patients. According to the literature on integrated care, a paradigm shift is now required for health services to become more centered on what matters to patients. Goal-oriented care is designed to elicit individual patients' health-related goals and align care with these goals. In Norwegian primary health care, a goal-oriented intervention around care planning has been applied in integrated care for older patients with multimorbidity. Care planning is based on patients' answer to the question "What matters to you?". Little is known about the experiences and interactions that ensue when this intervention is carried out.

This thesis explores how patient participation emerges when the WMTY intervention is carried out. It explores integrated care as emergent social process. The aims are, firstly, to investigate normative integration, that is, how values and goals for the intervention are shared between different levels of the health services. This is operationalized through normative justifications for patient participation. Secondly, interpersonal integration is explored through the experiences related to patient participation and the interactions between health professionals and patients in care planning.

The three qualitative studies adopt a constructivist approach. They capture the perspectives of different actors and assess the implications of their interactions. The data was collected in four municipalities in Western Norway between September 2018 and December 2019. Prescriptive documents for the intervention included a governmental

white paper, a guideline for patients with complex needs, and written checklists and intervention tools for health professionals. Direct observations of ten care-planning meetings were combined with individual interviews with patients after their meetings. Four focus-group discussions included a total of 24 health professionals. Data analyses include content analysis, grounded theory, and stepwise-deductive induction.

The results regarding normative integration between levels of health services indicate that the normative justifications for patient participation in the care planning intervention ranged from a principle of individualization at the macro-level to one of standardization at micro-level. This appeared through an examination of prevailing institutional logics, the number and range of which decreased moving down the levels (Paper 1). Health professionals took four different approaches to involving patients in the intervention: motivating for goals, vicariously setting goals, negotiating goals, and specifying goals. These four approaches are different ways in which health professionals shared responsibility for goal setting with patients (Paper 2). In the care-planning meetings, health professionals, relatives, and patients had different perceptions about what goals to set. Some patients experienced uncertainty in that the trajectory of their illness and their ability to participate in the rehabilitation process were unpredictable. The way uncertainty was handled in the meetings was associated with the level of patient participation and patients' temporal focus in care planning (Paper 3).

This thesis extends our understanding of normative and interpersonal integration of goal-oriented, integrated care. It illuminates how the social dynamics between actors and levels of health services emerge in goal setting for older patients with multimorbidity. Moreover, it provides insights about how and why the level of patient participation may vary in goal-oriented care for older patients with multimorbidity.



## 1. Introduction

Across countries in the Western world, the share of the population over 65 years of age is rapidly growing (Eurostat 2020). The older population is expected to nearly double in the next decades, reaching 27% in 2050 (Organization for Economic Co-operation and Development (OECD) 2017). Most older persons have multimorbidity, which is the coexistence of two or more chronic conditions (Xu, Mishra, and Jones 2017; Barnett et al. 2012). They often have complex needs involving high utilization of health services, with risk of acute disease and hospitalization, repeated disease episodes, and needs for long-term care (Schaink et al. 2012; Murray et al. 2005; Palmer et al. 2018).

In Western countries, more of health care is being moved out of hospitals. One aim in health policy is to promote aging in place. The municipalities receive older patients with multimorbidity from hospitals earlier than previously (Damery, Flanagan and Combes 2016; Forsyth and Molinsky 2020). To structure health service delivery, improvement of integrated care for patients with multimorbidity in primary health care is ongoing (World Health Organization (WHO) 2016a; 2016b; Palmer et al. 2018). Integrated care is coordinated within or across services; it is pro-active, multidisciplinary, and person-centered (Leijten et al. 2018, 13). This thesis focuses on the person-centered component; the patient is assumed to be at the heart of this model of care (Amelung et al. 2017).

Patient participation in care planning is key to the provision of high-quality, person-centered care as experienced by patients. Patient participation is believed to increase patients' health, as unmet healthcare needs are identified and patients' self-management abilities increase, which in turn reduces service utilization (Butterworth et al. 2020; Halabi et al. 2020; Ebrahimi et al. 2021). However, patient participation is not a common practice, occurring to only a low extent in clinical settings (Pel-Littel et al. 2021; Couët et al. 2015; OECD 2019a). Older patients with multimorbidity are less frequently involved in care planning than younger patients, even though they tend to prefer an active role

(Halabi et al. 2020; Bunn et al. 2018; Dyrstad et al. 2015). Patient participation is challenging because patients may have several diseases resulting in several potential goals for service delivery (Butterworth et al. 2020; Berntsen et al. 2015; Fried, Street and Cohen 2020). These goals often vary between institutions, health professionals, and patients (Rose, Rosewilliam and Soundy 2017; Palmer et al. 2018; Bunn et al. 2018).

Goal-oriented care includes a set of practices in which health professionals explore patients' goals, preferences, and needs. Patients participate in formulating individual goals for service delivery, and decision-making and care are centered around these (Vermunt 2018, 15). The literature on integrated care states that this requires a paradigm shift in the health system—a departure from a traditional disease- and problem-oriented service delivery, in which the patients have a passive, dependent role and health professionals are the experts, towards service delivery attuned to and oriented around each patient's individual goals (Berntsen et al. 2018; Steele Gray et al. 2020; Reuben and Tinetti 2012). Goal-oriented care applied in integrated care is in this thesis labeled goal-oriented, integrated care. Knowledge about how this materializes in practice for older patients with multimorbidity is important for patient participation in future health service delivery.

In Norway, improvement of integrated care pathways for older patients with multimorbidity is ongoing. This care pathway targets patients who go through hospitalization and/or admission to post-acute rehabilitation facilities and then return to their homes (Norwegian Directorate of Health 2018). A care-planning intervention in which health professionals initiate a dialogue with patients about “What matters to you?” (WMTY), is applied to provide individual patients with greater opportunity to participate in the formulation of their health care (Norwegian Directorate of Health 2018a; Norwegian Ministry of Health and Care Services 2018). This is believed to structure the follow-up of individual patients and ensure their participation in formulation of health service delivery. However, social processes within integrated care are emergent, and therefore the outcomes of service delivery cannot be predefined (Peterson et al. 2019; Singer et al.

2020). Thus, this thesis explores how patient participation emerges within the WMTY intervention, both across levels of health services and in how patients and health professionals interact.

In the following part of this introduction chapter, I explain the concept of goal-oriented care and describe key characteristics of older patients with multimorbidity. The section also examines previous research on goal-oriented care practices. Finally, the conceptual framework and the study aims of the thesis are presented.

### 1.1 Goal-oriented, integrated care and patient participation

For decades, it has been an aim of primary health care to create conditions in which people participate in decisions about their health care in line with their own goals and objectives (WHO 1978; WHO 2018). Several justifications for patient participation have emerged during recent decades out of social movements, developments in the field of medicine, and re-organization of health care (Halabi et al. 2020). Patients have been entitled to participate as citizens in society with rights for their voices to be heard, as consumers of health services with freedom of choice, and more recently as co-producers of their own service delivery (Dent and Pahor 2015). The meaning and practices of patient participation may vary across healthcare systems, local contexts, and patient groups (Thompson 2007). How older patients with multimorbidity are entitled to participate in goal-oriented, integrated care will be explained in the next paragraphs.

Goal-oriented care was first described by Mold, Blake and Becker (1991) as decision-making between physicians and patients, with a “goal” defined as an outcome desirable to the patient. The concept has the last decade appeared in the literature about patients with multimorbidity (Reuben and Tinetti 2012; Vermunt 2018; Berntsen et al. 2018; Steele Gray et al. 2020). Goal-oriented care means that health professionals explore patients’ goals, preferences, and needs and let these direct health service delivery (Vermunt 2018). Goal-oriented, integrated care can be understood through the interrelated concepts of

integrated care, person-centered care, and patient participation. Each of these concepts will be briefly explained in turn.

This thesis is carried out in a context where goal-oriented care gets applied through integrated care for older patients with multimorbidity. The word “integration” in integrated care comes from the Latin word *integer*, meaning “whole” or “entire.” The essence of integrated care is that all parts of the health system, *including patients*, work together as a unified whole (WHO 2016c). A common concern across both empirical and conceptual work on this subject is unity in the face of fragmentation as well as application of methods to achieve this unity (Hughes, Shaw and Greenhalgh 2020; Singer et al. 2020; Valentijn et al. 2013). Integration often refers to coordination of service delivery, but in this thesis, it specifically focuses on the essential matter of patient participation in this process. From a patient perspective, integrated care can mean “I can plan my care with people who work together to understand me and my carer(s), allow me control, and bring together services to achieve the outcomes important to me” (Redding 2013, 322). “Integration” is the process by which actors come together. Integrated care is the outcome as experienced by patients (Goodwin, Stein and Amelung 2017).

Even though the term “integrated care” has different meanings, and the body of literature is heterogenous (Hughes, Shaw and Greenhalgh 2020; Armitage et al. 2009), there is consensus about person-centered care being at the core of integrated care (Amelung et al. 2017; Leijten et al. 2018; Calciolari et al. 2021). In this context, “person-centered care” can be defined in a similar way as “goal-oriented care”: “individuals’ values and preferences are elicited and, once expressed, guide all aspects of their health care, supporting their realistic health and life goals” (American Geriatrics Society 2016, 16). The main objective of person-centered care is a life that is meaningful to the patient (Håkonsson Eklund et al. 2019). The patient is not seen as a diagnosis but rather as a whole person, so that care addresses physical, mental, emotional, and social aspects of the patient’s life. Both

person-centered care and patient participation require a collaborative relationship between health professionals and patients, one characterized by an individualized focus, shared decision-making, and shared responsibility and involving the patients' families (Ebrahimi et al. 2021, Kitson et al. 2013, Halabi et al. 2020). Patient participation is understood by some scholars as a generic concept, eclipsing the concept of person-centered care (Casado, Sousa and Touza 2020; Thórarinsdóttir and Kristjánsson 2014).

Another apt clarification concerns the relation between patient participation and shared decision-making. Integrated care as a conceptual framework often refers to shared decision-making, which means reaching a mutual understanding of problems, preferred goals, and actions (Palmer et al. 2018; Charles, Gafni and Whelan 1997, Coulter et al. 2015). The term “shared decision-making” has previously referred to the situation in which professionals present treatment options to patients; more recently, however, it has been used for decisions about the care process as well, including individual needs and future goals in chronic diseases (Palmer et al. 2018, 5; Coulter et al. 2015). Shared decision-making can be viewed as involving a high level of patient participation (Thompson 2007). This thesis uses the concept of patient participation, which is more nuanced in that it allows for the fact that patients can participate to different extents or levels (the levels will be explained at page 32). Moreover, goal-oriented care is not limited to (shared) decision-making. Patients can take an active role in their health service delivery and health.

In sum, “goal-oriented, integrated care” refers to health service delivery that is person-centered and integrated so that the actors within the health system, including patients, work together as a unified whole with a common goal—the patient’s personal goal (Steele Gray et al. 2020; Berntsen et al. 2018). These concepts reflect a systems perspective (integration), a health professional perspective (person-centered care), and a patient perspective (goal-oriented care). Notably, all these concepts have a normative basis in

that they express problems and ideals. Arguably, patients' concerns are not adequately represented in current definitions of integrated care, which focus primarily on the organizational perspective (Lawless et al. 2020). Goal-oriented care can be regarded as a specific operationalization of integrated, person-centered care (Berntsen et al. 2019). Goal-oriented care is a catalyst for achieving these aims because actors in health services are brought together, they let patients participate in the formulation of service delivery, and they work towards patients' goals (Steele Gray et al. 2020). This ideal integration process in which the actors work as a unified whole (Singer et al. 2020) can make care planning individualized and goal-oriented and encourage the patient to participate as a respected and autonomous individual (Kitson et al. 2013; American Geriatrics Society 2016). In this context, there is little evidence relating specifically to decision-making and goal setting with older patients with multimorbidity and complex needs (Lenzen et al. 2017; Bunn et al. 2018; Baker et al. 2021; Steele Gray et al. 2020). This thesis contributes to address this knowledge gap.

## 1.2 Older patients with multimorbidity and complex needs

In multimorbidity, each condition is either a non-communicable disease, a mental health disorder, or an infectious disease of long duration. This definition is widely used in research (Johnston et al. 2018; The Lancet 2018). Because there are several definitions of multimorbidity, the prevalence is not exactly measured. Based on cross-sectional studies, it is estimated to be 65% of people over 65 years and 85% for the 85-year-old group (Marengoni et al. 2011; Palmer et al. 2018). The limit for "old" age can be set at 65 years, and the limit for "oldest old" at 80 years. The average life expectancy is 80 years across OECD countries (OECD 2017, 20). The inter-related conditions in multimorbidity, combined with chronological age, qualifies the cases of these patients as complex (Barnett et al. 2012).

Patients' symptoms and the severity of their diseases are less frequently included in definitions of multimorbidity. Common reported diseases are diabetes, stroke, cancer, ischemic heart disease, chronic obstructive pulmonary disease, heart failure, depression, kidney disease and osteoarthritis. Symptoms may include back pain, lack of energy, visual impairment, urinary incontinence, gastrointestinal problems, dizziness, sleeping disorders, or headache (Willadsen et al. 2016; Eckerblad et al. 2015). The most common reported consequences of multimorbidity for patients is its associations with polypharmacy, functional decline with deterioration in self-management abilities, and poorer quality of life (Coulter et al. 2015; Marengoni et al. 2011; Ryan et al. 2015). Functional decline in older people is associated with falls and fall-related injuries (WHO 2017).

Patients with multimorbidity have "complex needs" (Palmer et al. 2018). From the perspective of patients, this entails that multimorbidity is more than the sum of the diagnoses (Coventry et al. 2015; Koch, Wakefield and Wakefield 2015). The lived experience can differ from the biomedically imagined concept of multimorbidity. Some individuals experience normality (Porter, Ong and Sanders 2020), while others experience multimorbidity as an encounter with complexity. Illness impacts both physical and psychological health, everyday life, and social life (Coventry et al. 2015; Koch, Wakefield and Wakefield 2015). Patients experience functional challenges and difficulties in dealing with physical and emotional symptoms, among which depression, pain, and fatigue are prominent (Liddy, Blazkho and Mill 2014). Patients often want to live in their homes for as long as possible, but scant research has been done on this topic among persons with multiple impairments and frail health (Meijering 2021). People with multimorbidity are likely to rely on the support of informal caregivers (Price et al. 2020). Furthermore, the future is uncertain for them because the course of their diseases in combination with old age is unpredictable: a typical trajectory is prolonged gradual decline in function from an already low baseline. In other cases, acute deterioration followed by some degree of

recovery may occur several times. There is a risk that minor episodes of disease can be fatal if they occur in combination with declining reserves (Murray et al. 2005).

Furthermore, the needs of patients are complex for the health system to handle. Patients can have high utilization of health services, with risk for acute disease and hospitalization, repeated disease episodes, and need for long-term care (Manning and Gagnon 2017; Schaink et al. 2012; Murray et al. 2005). The goal of service delivery is subject to variation between institutions, health professionals, and patients (Rose, Rosewilliam and Soundy 2017; Palmer et al. 2018; Bunn et al. 2018). Moreover, guidelines for single diseases are not applicable as they do not fully cover patients' problems (Mold, Blake and Becker 1991; Muth et al. 2014). Sometimes it is too demanding or almost impossible to address multiple health and/or social problems simultaneously in the way that the multiple guidelines would require (Ong, Lee and Lee 2020). Health professionals need to consider that illness impacts several areas of patients' life, including emotional, psychological, and behavioral attributes, their environment, and social relations (Manning and Gagnon 2017; Schaink et al. 2012). The complexity of these patients' needs is a justification for goal-oriented, integrated care.

### 1.3 Goal-setting interventions

Goal-oriented care is attained through health service interventions. An intervention is "an act performed for, with or on behalf of a person or population whose purpose is to assess, improve, maintain, promote, or modify health, functioning or health conditions" (WHO 2021). Note that integrated care pathways can be referred to as complex interventions (Vanhaecht et al. 2010). However, in this thesis, the "intervention" is goal setting in care planning. Conceptually speaking, this is a component of service delivery at the micro-level in integrated care (Leijten et al. 2018) that is initiated by the upper levels. Goal setting is also included in the guideline "*Multimorbidity: clinical assessment and management.*" According to this guideline, health professionals should encourage patients to clarify what



is important to them in order to include their personal goals, values, and priorities in an individualized care plan (National Institute for Health and Care Excellence 2016).

Goal setting has previously been used for adults with a chronic disease, such as diabetes (Coulter et al. 2015; Levack et al. 2016). In the 2010s, multiple procedures appeared in the literature for setting goals with older patients with multimorbidity. In essence, the procedures are similar: Goal setting involves one or several forward-looking conversations between patients and health professionals about what matters to patients. Patients can influence the discussion, and the choice of goals and priorities for service delivery is not prespecified by professionals (Coulter et al. 2015). Goal setting can include different types of health-related goals: reducing symptoms or improving physical functioning or wellbeing. The goals can also have social dimensions or be related to life values (also called “fundamental goals”). Goals can span more than one of these dimensions (Reuben and Jennings 2019; Vermunt et al. 2017; Elwyn and Vermunt 2020). Often a goal hierarchy is set, where the highest-level goal is broken down into subgoals and tasks (Elwyn and Vermunt 2020; Berntsen et al. 2015). In some goal-setting instruments, patients score the perceived severity of their problems and measure goal attainment over time (Law et al. 1990; Rietkerk et al. 2021; Reuben and Jennings 2019). “Collaborative goal setting” is a concept referring to a process by which health professionals and patients agree on a health-related goal (Vermunt et al. 2017). Often, goal setting is intended to enhance patient self-management. The theoretical underpinnings of goal-setting interventions in goal-oriented care are not always explicitly stated (Lenzen et al. 2017; Miller et al. 2020; Coulter et al. 2015).

Two overlapping goal-setting concepts are not included in this thesis. First is patient priority-directed decision-making, in which patients and physicians choose medical treatment options in line with what patients are willing and able to do (Tinetti et al. 2016; Tinetti et al. 2021). Second is the setting of goals of care in advanced care planning, where

patients with advanced chronic diseases are asked how they would like to be cared for in the final months of their life (Gonzales et al. 2019).

### 1.3.2 The Norwegian “What matters to you?” intervention for older patients

The question “What matters to you?” was first introduced in an article in the *New England Journal of Medicine* in 2012. Beyond “What is the matter?”, physicians were recommended to ask patients “What matters to you?” as a way of implementing patient-centered care and shared decision-making (Barry and Edgeman-Levitan 2012). Since then, the Institute for Healthcare Improvement in the United States has been a central actor in spreading the practice of asking this question to numerous countries across the world as a slogan and care-planning tool and as a basis for patient-centered care (Institute for Healthcare Improvement 2019; 2021).

The question WMTY is applied in a Norwegian care planning intervention, which in integrated care pathways is carried out as follows. After an acute disease episode, individual patients are allocated a defined amount of health care services by their municipalities. Through an application to receive services, considered by an office for allocation of services in the municipality, patients are allocated services based on an assessment of physical functioning and needs (Norwegian Directorate of Health 2017). Then, the intervention is carried out in care-planning meetings. Health professionals ask the patients “What matters to you?” as a basis for care planning, so that patients can participate in formulation of their service delivery. Health professionals are recommended to actively allow patients’ preferences, values, and needs to direct the service delivery (Norwegian Directorate of Health 2018a; 2017). According to a Norwegian guideline for WMTY, the goals should help patients to increase their level of independence and self-management (Norwegian Directorate of Health 2018). Either one health professional and the patient set the goal during one or several conversations or else the goals are set during a multi-professional care-planning meeting. Patients’ relatives are sometimes

present in the meetings. To ensure continuity of care, health professionals should repeat the WMTY intervention at each transition in the patient's care pathway. A goal for the care pathway is formulated and documented with the understanding that patients and health professionals will work together towards this goal in the coming weeks.

This thesis explores WMTY because research on the application of the WMTY intervention in clinical settings is scarce and there is little knowledge about how goal-oriented care is produced in an integrated-care context. Goal-oriented care is a new practice, being applied with older patients as part of "usual care" and spreading to different settings in primary health care (Institute for Healthcare Improvement 2021; Reuben and Tinetti 2012). There are few empirical studies of how this approach to care is understood across different levels of health services and how it materializes in clinical practice in municipalities and among health professionals and patients. More research about the experiences of patients with multimorbidity is also called for, because whether care is goal-oriented and integrated or not depends on the patients' experiences (Singer et al. 2011; Rijken et al. 2019).

#### 1.4 Goal-oriented, integrated care practices

##### 1.4.1 Application of goal-oriented, integrated care in health services

A gap exists between the multimorbidity guidelines that recommend eliciting patients' goals in care planning and the evidence base (Butterworth et al. 2020). Currently, there are few literature reviews that consider goal-oriented care and integrated care together (Berntsen et al. 2019). Most research on integrated care for older patients is from North America, Europe, and Oceania (Briggs et al. 2018). From 2010 to the present, integrated care has increasingly been implemented in European countries or regions (Rijken et al. 2016; Struckmann et al. 2018). Frequently used outcome measures of care planning activities within the context of integrated care include rates of hospitalization, cost-effectiveness, functional status, satisfaction with care, and quality of life. The evidence for

all outcome measures is still mixed and insufficient (Smit et al. 2019; Hopman et al. 2016; Looman, Huijsman and Fabbriotti 2019; Smith et al. 2021).

Additionally, there is little evidence on outcomes to support or recommend goal setting in rehabilitation of older adults (Ford et al. 2019; Smit et al. 2019). A review of rehabilitation across diverse patient groups found no conclusive evidence that structured goal setting changed outcomes of patient participation, activity, or engagement (Levack et al. 2016). Goal-setting activities led to inclusion of problems, goals, and actions in care plans (Vermunt et al. 2017). A recent Cochrane review found that goal setting probably increased the number of older patients who discussed their priorities, but the current evidence base regarding the *effects* of interventions aimed at involving older people with multimorbidity in decision-making about their healthcare is limited (Butterworth et al. 2020). Results that indicate little difference between goal setting and usual care could be due to study weaknesses—for example, if both the control and intervention groups have similar policy at macro-level (Raus, Mortier and Eeckloo 2020), and “usual care” practices are already to some extent orientated towards the goals of patients (Smit et al. 2019). Other aspects include difficulties in separating components of integrated care; success is not necessarily specific or measurable (WHO 2016c).

Research on integrated care tend to be system- rather than person-centered (Briggs et al. 2018). Few studies measure patient participation or related concepts as an outcome (Butterworth et al. 2019). This seems odd given that person-centered care is regarded as essential to integrated care (Leijten et al. 2018; Palmer et al. 2018; WHO 2016c). Most European programs aim to let patients define goals and participate in the decision-making regarding their treatment, which has increased patients’ satisfaction with care (Czypionka et al. 2020; van der Heide et al, 2018). However, difficulties in tailoring integrated care services to the needs and wishes of older persons remain challenging across contexts (de Bruin et al. 2020; Ebrahimi et al. 2021).

Integrated care models have been criticized for being too comprehensive, involving the whole health system and context, which makes integration difficult to achieve (Harvey et al. 2019; Hughes, Shaw and Greenhalgh 2020). Some authors have therefore asked what can be realistically implemented at a system level, and others have asked what health outcomes can be expected among older patients (American Geriatrics Society 2016; Looman, Huijsman and Fabricotti 2019). Despite the lack of demonstrated outcomes, some authors argue that goal setting is desirable from an ethical point of view, because the preferences, values, and autonomy of patients are respected (Smit et al. 2019; Levack et al. 2016).

Because the outcomes are uncertain, and person-centered care is hard to implement in practice, this thesis focuses on the *processes* through which goal-oriented, integrated care is produced. Goal-oriented, integrated care requires a shift in both the structure and the culture of the health system (Threapleton et al. 2017; Steele Gray et al. 2020). The structural elements can include, for example, recommendations regarding patient goal setting in health policies (WHO 2016c), in multimorbidity guidelines (National Institute for Health and Care Excellence 2016), or in care pathways (Norwegian Ministry of Health and Care Services 2018). The structure is assumed to enhance the cultural, or social, side of integrated care (Singer et al. 2020). One element of organizational culture that is particularly important to the achievement of goal-oriented care is that actors at the different levels of health services share goals. This includes the beliefs health professionals hold about the value of this approach to care and about how and why patients should participate (Steele Gray et al. 2020; Threapleton et al. 2017; Briggs et al. 2018). This issue needs further attention, as indicated by the very fact that a “paradigm shift” in mindset and practices is proposed (Reuben and Tinetti 2012). Furthermore, strategies for change can be formulated on the macro- (system), meso- (organizational), and micro- (clinical) level of health services. These levels are intertwined, because establishing change at a certain level often requires actions at other levels (van der Heide et al. 2016). Studies of

integrated care for older people often focus on the micro-level, while there is less information regarding integration at the meso- and macro-level (Briggs et al. 2018). Factors at all levels can jointly influence adoption of integrated, person-centered care. The outcomes are better when healthcare professionals are committed to this model of care (Kirst et al. 2017). Thus, the culture at the meso- and micro-level can be a barrier to the implementation of formal integrated care policies. Change in culture may take time (Threapleton et al. 2017).

The current research acknowledges that contexts differ and that strategies for achieving integrated care may require adjustments to local contexts (Threapleton et al. 2017). More research is needed on integrated care across different European countries and care settings, such as community and primary health care (Monaco et al. 2020). Case studies are called for (Stoop et al. 2020), and the Norwegian WMTY intervention is typical of the ongoing attempts to improve services. Little is known about goal-oriented care practices that are applied in care pathways for all older patients with multimorbidity. In this regard, the micro-level interactions between health professionals and patients are important; they are addressed in the subsequent paragraphs.

#### 1.4.2 Patients' experiences and interactions in goal setting

Goal-oriented, integrated care requires an active patient role (Steele Gray et al. 2020). Patients with multimorbidity in primary health care settings constitute a heterogeneous group having different views and ways of participating. These can vary with the medical complexity of their conditions and the personal resources they have for managing health and care. Some are less focused on the way in which care is delivered, while others proactively take charge of their own care (Kuipers, Nieboer and Cramm 2020; Rijken and van der Heide 2019). Some patients lean towards leaving the decisions to health professionals, particularly decisions related to referral. Letting patients choose the degree of their participation is beneficial to their experiences of the care process (Czypionka et al. 2020; Lawless et al. 2020).

Characteristics of older patients with multimorbidity that are beneficial to decision-making are seldom mentioned. One review found that some patients with multimorbidity feel more experienced within the health service than patients with single diseases. They perceive that the chronic aspect of their conditions has given them greater knowledge about their condition and preferences (Pel-Littel et al. 2021).

Older patients want to be involved in decisions about their care and treatment, in accordance with their needs, preferences, and capacities at the time of the encounter. Patients generally want to participate more than they are allowed to, and they often experience that care is not “centered” on them (Lawless et al. 2020; Casado, Sousa and Touza 2020; Dyrstad et al. 2015). They sometimes disagree with health professionals on the plan of care (Koch, Wakefield and Wakefield 2015). The level of patient participation varies among older patients, and often it is low (Bunn et al. 2018; Halabi et al. 2020; Dyrstad et al. 2015). The opportunity to define goals or participate in decision-making is highly valued by many patients (Czypionka et al. 2020; Boye et al. 2019; Rose, Rosewilliam and Soundy 2017; Lawless et al. 2020). However, goal setting is new to many patients, and they therefore have difficulty understanding what is expected of them (Rose, Rosewilliam and Soundy 2017; Boeckxstaens et al. 2016). One qualitative study found that some patients seemed to have accepted their situation and did not feel the need to set goals. Some patients appeared to consider personal goals as selfish. For others, stressors such as pain or fear predominated over goal setting (Boeckxstaens et al. 2016; Baker et al. 2021). The desire to participate is lower in acute phases of disease, when the number and severity of diseases are high, or when patients experienced ongoing fatigue (Thompson 2007; Chi et al. 2017; Baker et al. 2021). Moreover, patients’ preferences can vary over time (Etkind et al. 2020; Bunn et al. 2018).

It is unclear what happens in care-planning meetings, and which aspects play a role in the process of formulating goals (Boeckxstaens et al. 2016; Coulter et al. 2015; Lenzen et al. 2017). The WMTY intervention has only recently been applied to this heterogenous

patient group, and research on patients' experiences in the Norwegian context is called for (Nilsen, Söderhamn and Dale 2019). Considering that patients are expected to take an active role in integrated care, while some patients tend to leave decisions to healthcare professionals (Amelung et al. 2017; Czypionka et al. 2020), more insight into patients' experiences is needed to understand how goal-oriented, integrate care is produced.

#### 1.4.3 Health professionals' experiences and interactions in goal setting

Integrated care for older patients with multimorbidity is delivered by a multidisciplinary team of health professionals (Leijten et al. 2018; Palmer et al. 2018), which may include nurses, auxiliary nurses, physicians, physiotherapists, occupational therapists, and case managers. The different task-spaces of health professionals from different occupations can mean that their focuses in goal setting do not always align (Stoop et al. 2020).

However, this thesis focuses on how the team of health professionals includes patients in decision-making. This is crucial in implementing person-centered care in out-of-hospital settings. It requires health professionals to be flexible, spend sufficient time, and have patience in encounters with patients (Ebrahimi et al. 2021).

Health professionals perceive that goal setting increases collaboration with patients and makes their practices more person-centered than previously (Stoop et al. 2020; Ford et al. 2019; Rose, Rosewilliam and Soundy 2017). However, they do not consistently practice this approach and, in some cases, even work in opposition to it (Lawless et al. 2021). One common barrier is that many health professionals function as the principal decision-maker and frame the situation differently than patients. The medical focus is strong, making it difficult to set goals that are meaningful to the patient (Rose, Rosewilliam and Soundy 2017; Treapleton et al. 2017; Melin et al. 2019). Health professionals can perceive the process of negotiating and formulating goals with older patients with multimorbidity as challenging. They see a need to educate patients to succeed and perceive that some patients do not naturally articulate goals (Boeckstaens et al. 2016; Bodenheimer and Handley 2009). Moreover, health professionals perceive that some patients are



unmotivated or take little responsibility for setting goals. Others have problems with communication or cognition. Health professionals also perceive some patients as less able to set goals (Rose, Rosewilliam and Soundy 2017; Lenzen et al. 2016). Health professionals may see a need to control goal setting by excluding specific patients or specific psychosocial goals, as they feel responsible for using their professional knowledge as well as for respecting contextual time pressures and financial constraints when they select goals (Rose, Rosewilliam and Soundy 2017; Lenzen et al. 2016; Levack et al. 2011).

As described above, goal setting is a complex interactional activity. There are studies explaining what health professionals can do to engage patients in goal setting—detailing, for example, the dimensions of goals and offering goal-setting tools (Lenzen et al. 2017; Vermunt et al. 2017; Elwyn and Vermunt, 2020). However, health professionals' ways of interacting with patients need to be individualized to facilitate their participation (Bunn et al. 2018; Kuipers, Nieboer and Cramm 2020; Rijken and van der Heide 2019). Missing, at present, is a conceptualization of the approaches health professionals take to set goals with older patients with multimorbidity.

### 1.5 Conceptual framework for the thesis

Goal-oriented, integrated care can be understood and studied as emergent set of practices rather than an intervention that, because of its structure, leads to predetermined outcomes (Hughes, Shaw and Greenhalgh 2020; Steele Gray et al. 2020). Integration is the making of a unified whole from distinct and interdependent organizational components. Organizational and social features and courses of action or activities are unified (Singer et al. 2020, 197). This occurs as a dynamic interplay between context, actors, and structure (Embuldeniya et al. 2018; Valentijn et al. 2013). The “comprehensive theory of integration” synthesizes and extends previous models of integration (Singer et al. 2020). In this theory, integration has five dimensions: structural, functional, process, interpersonal, and normative. These dimensions overlap, and aspects within a specific dimension of integration can potentially be explained within other

dimensions as well. Structural and functional integration refers to organizational features like policies and rules. Process integration describes activities in service delivery, like care planning. Most past work has focused on those three dimensions, and they are thought to enhance collaboration and common goals for health service delivery (Peterson et al. 2019; Singer et al. 2020). This thesis focuses primarily on normative and interpersonal integration, which are the social dimensions: what people believe and how they act together when they produce integrated care (Singer et al. 2020). This social side of integration is a “process of encountering, confronting, and unifying the desires of various parties in service of creating a collective mind, feeling, and will” (Singer et al. 2020, 198). This social side is important to examine. Written rules of organizations, like policies and prescriptions, are encoded in systems and functions. However, these are not always expressed in the actors’ beliefs and interactions (Singer et al. 2020). The process of integration is continuously generated or impeded (Embuldeniya et al. 2018).

Patient participation can be shaped by these integration types. It spans all levels of health services and is shaped by characteristics of macro-level society and government, meso-level healthcare organization, and the collaboration between patients and health professionals at micro-level (Halabi et al. 2020).

#### 1.5.1 Normative integration

Normative integration is defined as “the development and maintenance of a common frame of reference (i.e., shared mission, vision, values and culture) between organizations, professional groups and individuals” (Valentijn et al. 2013, 8). Normative integration is a mechanism that links the macro-, meso-, and micro-level of health services (Steele Gray et al. 2020). These different levels of the healthcare system should be addressed when one examines whether processes with common objectives occur vertically (Monaco et al. 2020; Valentijn et al. 2013). Few studies of normative integration within integrated care exist (Singer et al. 2020; Zonneveld et al. 2018). Normative justifications for patient

participation can be an element in understanding normative integration of goal-oriented care.

To examine normative integration, an organizational analysis is suitable, since integrated care can be understood as dynamic, emergent, and inseparable from context (Hughes, Shaw and Greenhalgh 2020). Ideas of complexity of organizational work, such as “institutional logics,” can open the way for such understanding. Institutional logics are belief systems within the society that transcend the macro to micro level and vice versa. Institutional logics provide actors with frames of reference that precondition their sensemaking and choices. One common typology includes the seven institutional logics: those of religion, the market, the state, community, and family as well as professional and corporate logics (Thornton, Ocasio, and Lounsbury 2012). This perspective suggests that actors within the health services can be driven by multiple institutional logics. These actors can behave, at least in part, in accord with the values, norms, and goals associated with the respective logics by which they are driven (Thornton, Ocasio, and Lounsbury 2012). Central to the context of goal-oriented, integrated care is how patient participation in care planning is justified vertically between levels of health services.

#### 1.5.2 Interpersonal integration

Interpersonal integration is the extent of collaboration or teamwork among health professionals, nonprofessional caregivers, and patients. Patient participation, or person-centeredness, is an essential component of interpersonal integration (Singer et al. 2020, 199; Calciolari et al. 2021). Patients’ values and preferences are elicited and included in care planning so that health service delivery can form a single or coherent process (Singer et al. 2020, 201). The patient co-produces the care process, and the responsibility for finding a common ground is shared between the professional and the patient (Valentijn et al. 2013). This corresponds to how person-centered care requires a cooperative relationship between health professionals and older patients—one built on communication, respect, and shared responsibility (Kitson et al. 2013; American Geriatrics

Society 2016). Hence, this thesis focuses on the interactions of health professionals and patients: how they collaborate and how patients participate within the WMTY intervention.

### 1.5.3 Levels of patient participation

The notion of levels of patient participation is an important concept in the study of integration because previous research indicates that patients participate to varying extents. Several taxonomies of levels of patient participation have been developed over the past decades (Arnstein 1969; Charles, Gafni and Whelan 1997; Thompson 2007). In the context of person-centered health policies and goal-oriented, integrated care, shared decision-making is the highest level—the ideal to be aspired to (Palmer et al. 2018). The actual levels of patient participation, however, vary (Table 1). In this thesis, these levels are determined by the extent to which patients’ values, preferences, and needs (i.e., their goals) are elicited and guide decision-making regarding service delivery.

**Table 1: Levels of patient participation**

<b>High</b>	In “shared decision-making,” the parties agree on the decisions/goals. Health professionals’ knowledge of diagnoses and treatment is on a par with patients’ knowledge about the impact of disease on their daily lives.
<b>Medium</b>	A “dialogue,” or two-way communication, is achieved in which both parties ask questions and evaluate options. Power, control, or responsibility in decision-making are not necessarily shared, and patients goals do not fully guide decision-making.
<b>Low</b>	Information is shared or sought, but this level is characterized by lack of information provided to patients, lack of dialogue about what matters to patients, the meaning of goal setting not being explained, or patients merely being informed about decisions already taken by health professionals. The parties disagree on goals.
<b>Exclusion</b>	Patients are excluded by health professionals or do not involve themselves in decision-making.

Based on Bunn et al. 2018; Charles, Gafni and Whelan 1997; Coulter et al 2015; Rose, Rosewilliam and Soudy 2017; Thompson 2007; Vermunt et al. 2017.

In sum, patient participation, materialized in normative and interpersonal integration, is central to the achievement of goal-oriented, integrated care.

## 1.6 Rationale and aims of the thesis

Given the traditionally low level of participation of individual older patients with multimorbidity in care planning, the purpose of this thesis is to address the knowledge gap about how goal-oriented, integrated care for older patients with multimorbidity materializes in practice. This knowledge is important to promote patient participation in future service delivery.

The “What matters to you?” intervention in integrated care pathways in Norwegian primary health care is believed to structure the follow-up of individual patients and ensure their participation in formulating health service delivery. The aim of this thesis is to explore the social side of integration, including how patient participation emerges in care planning when the WMTY intervention is carried out.

This aim is operationalized in exploring the two social processes of integration: Firstly, the thesis examines normative integration, looking at how justifications for patient participation materialize vertically from macro-to micro-levels of the health services. Secondly, it explores interpersonal integration, examining patients’ experiences of participation and the interactions that take place between health professionals and patients when the intervention is carried out. Three research papers, illustrated in Table 2, develops these ideas further.

### **Table 2: Overview of aims and research papers**

## The care planning intervention “What matters to you?”

NORMATIVE INTEGRATION	INTERPERSONAL INTEGRATION	
<p>Macro, meso, and micro levels’ justifications for patient participation in care planning (Paper 1).</p>	<p>Health professionals’ approaches to goal setting with patients in care planning (Paper 2).</p>	<p>Patients’ experiences and interactions in care planning (Paper 3).</p>

The research questions for the three papers are the following.

Paper 1: To examine vertical normative integration within health services for older patients with multi-morbidity: In what way are normative justifications for patient participation connected to different institutional logics? How do the constellations of institutional logics vary between the macro-, meso-, and micro-level of health services?

Paper 2: To explore health professionals’ experiences of interacting with older patients with multimorbidity in collaborative goal setting.

Paper 3: To explore the experiences older patients with multimorbidity have of participating in care-planning meetings and the types of interactions involved. What is the patient’s role in care-planning meetings? How do patients experience participation in such meetings?

The thesis explores this topic in the context of Norwegian primary health care.

### 1.7 The context: Norwegian primary health care

The Norwegian state is social democratic and universalist (Powell, Yörük and Bargu 2019). Hospitals are run by the national government and primary health care and long-term care by the municipalities in a single-payer model. Services for older people are broadly

accessible and are financed and organized by local municipal authorities (Saunes, Karinikolos and Sagan 2020; Ringard et al. 2013; Tikkanen et al. 2020). This overall responsibility of the municipalities may facilitate integration compared to countries that have several suppliers involved in follow-up of patients (Singer et al. 2020). Being legally independent, municipalities have a great deal of freedom in how to organize services within the boundaries of national laws. The municipalities differ in size, competence, and resources as well as in health professionals' geographical distances to patients (Ringard et al. 2013).

In health and care services over 90% of older patients have multimorbidity, on average 4–5 diseases (Grimsmo 2018). In 2016 about 70% of long-term care recipients received care at home, while 10% lived in assisted housing facilities, which are in between home and institutional care. About 20% of recipients lived in an institution or home with personnel available 24 hours a day (Mørk et al. 2016). The services included in this thesis are rehabilitation and long-term care, which takes place in low-technology community hospitals for rehabilitation (intermediate care units), in nursing homes, or in patients' homes. Patients aged 80 and over stay an average of 15 days in short-term or rehabilitation wards (Norwegian Directorate of Health 2016). Patients can also receive reablement, which is a time-limited rehabilitation service in their homes. Health professionals working with older patients include nurses, auxiliary nurses, physicians, physiotherapists, and occupational therapists. Some workers do not hold a health care education (Statistics Norway 2021). Note that general practitioners in primary care are not included in this thesis, because physicians in rehabilitation wards are involved through the phases of the care pathway examined here.

Life expectancy and performance of the health system in Norway are excellent in international comparisons. Norway was one of the first countries to promote people-centered care (OECD 2019b). Patients are entitled to participate in the design and delivery of their healthcare; this right should be adapted to the individual patient's ability to

receive and give information (The Act of Patients' Rights 1999 §3). In 2019, 2% of patients in time-limited rehabilitation stays had a formally documented individual plan to ensure coordination of care (Norwegian Directorate of Health 2018b). Hence, the care plans referred to in this thesis are formulated for each disease episode.

#### *Integrated care pathways and WMTY*

With an aging population and a growing need for care, one of the key challenges for the Norwegian health system is to strengthen primary and community care services (OECD 2019b). Since The Coordination Reform was launched in 2012 (Norwegian Ministry of Health and Care Services 2009), Norway has been improving integrated care pathways for older patients with complex long-term needs (Tikkanen et al. 2020). The integrated care pathway is for patients who go through hospitalization and/or admission to a post-acute rehabilitation facility and then are discharged back to home. This care pathway is based on two elements. Firstly, there are checklists from a generic care pathway "Patient Trajectory for Home-dwelling elders," which was developed in 2009 to structure the follow-up of patients regardless of diagnosis (Røsstad et al. 2015). Secondly, the WMTY intervention should be carried out before and after transitions in the care pathway (Norwegian Institute of Public Health, 2019a).

Actors from various healthcare settings can participate in a "learning network for whole, coordinated pathways in the municipalities." Regional learning networks aim to enhance the structure and person-centeredness of care pathways (Norwegian Institute of Public Health 2019a; Norwegian Ministry of Health and Care Services 2018). Here, information about how to carry out the WMTY intervention, along with a tool to ask WMTY based on the Patient Specific Functional Scale (Stratford et al. 1995) was suggested for implementation, as well as care pathway checklists and recommendations of how to measure improvement of care processes (Norwegian Institute of Public Health 2019b; 2019c).



The WMTY intervention is promoted in two documents at national level. Firstly, the health care reform “A full life – all your life — A Quality Reform for Older Persons.” One of the priority areas is to increase individual patients’ opportunity to formulate their care. This governmental white paper was released in 2018, and the implementation period in primary health care is from 2019 to 2023 (Norwegian Ministry of Health and Care Services 2018). There is little research on how this reform is adopted in local settings. Despite this being the first white paper describing the WMTY intervention, previous health policy was also built on principles of person-centered care and prioritized an active role for patients in formulation of their health services (Norwegian Ministry of Health and Care Services 2018; Norwegian Ministry of Health and Care Services 2011). Secondly, a guideline for follow-up of persons with complex needs for health and care services was released in 2018 (Norwegian Directorate of Health 2018a). This document contains normative recommendations that can be adjusted to local contexts. Its content is based on the guideline for patients with multimorbidity by the National Institute for Health and Care Excellence (2016) and the “Multimorbidity care model” (Palmer et al. 2018). This was the background for and the setting in which this thesis research was conducted. In the next part the methods used are presented.

## 2. Methods

### 2.1 Epistemological foundations

This study is guided by the epistemic commitments of social constructivism. Social constructivism is a perspective or set of beliefs about how to explore social process within a social setting (Berger and Luckmann 1967; Lincoln and Guba 2013). Knowledge can be viewed as a social product because people construct meanings as they engage with the world and make sense of it (Berger and Luckmann 1967). Some constructivists reject the existence of reality, or of objects, and view every fact as socially constructed (Lincoln and Guba 2013). This thesis does not reject an objective reality, and views constructions as

being shared, often, among many individuals and across cultures. However, some aspects of how phenomena are made sense of are local and specific in nature. The content of ideas can be dependent on the individual persons or groups holding them and can be shaped by their experiences, interactions, and communication with others (Guba and Lincoln 1994).

Therefore, researchers seek to capture the perspectives of different actors and then examine the implications of these (Patton 2015; Creswell 2014). The significance and meanings which people ascribe to objects and phenomena are important for those actions directed towards them (Schwandt, Lincoln and Guba 2007; Lincoln and Guba 2013). A constructivist approach is suitable for exploring goal-oriented, integrated care as being “produced” as an emergent practice (Hughes, Shaw and Greenhalgh 2020; Singer et al. 2020).

Constructivist epistemology is intersubjective; knowledge is not “discovered” but rather created and existing in the framework and time within which it is generated (Lincoln and Guba 2013). Knowledge construction is a product of the specific perceptions of the study participants, the interactions between the researcher and study participants, and the interpretation of the researcher (Guba and Lincoln 1994; Charmaz 2014). The objective is to generate not generalizable knowledge but perspectives that may be transferable. Knowledge in a field is individual reconstructions coalescing around consensus (Guba and Lincoln 1994). In constructivism, values are viewed as inseparable from research. The values of researchers are ineluctable in shaping the outcomes (Guba and Lincoln 1994). Therefore, the role of the researcher in this thesis is discussed at the end of this chapter.

## 2.2 Design

A qualitative research design is suitable for exploring the meanings that individuals and groups ascribe to things and the motivations behind their behavior. Qualitative studies render the complexity of situations because they are carried out in natural settings. This allows researchers to examine in detail the experiences of people as they live and interact

within their social worlds. Method triangulation captures multiple perspectives (Patton 2015, 684). The design of this study was emergent, allowing the research process to change during data collection (Creswell 2014).

### 2.3 Methods

To study normative integration, a case study was suitable. A case study can create a boundary and approach for studying a phenomenon in depth and within its real-life context (Yin 2014). The case studied here, of normative integration, included the health policy that triggered the WMTY intervention, a clinical guideline, health professionals' practices, and written intervention tools. This case study required triangulation of methods (Yin 2014). To study interpersonal integration, a grounded theory approach was suitable because it explores interactions and allows exploration of what the main concern of the participants is within the social process they participate (Glaser and Strauss 1967; Charmaz 2014). To guard against pre-defining what to look for in the interactions of health professionals and patients could generate new knowledge.

The methods that, separately and in combination, illuminated goal-oriented care in this study were direct observation, individual interviews, focus group discussions, and analysis of documents. Direct observation means to be in an ongoing social setting for the purpose of making a qualitative analysis of that setting (Patton 2015). This method allowed for examining how the WMTY intervention was carried out in real time, in its naturally occurring context, and provided information about things participants were not necessarily aware of (Morgan et al. 2017). Individual, face-to-face interviews gave a special insight into patients' subjective experiences and meanings. These experiences could best be communicated through spoken words or narratives (Charmaz 2014; Brinkmann 2018). Combining direct observations of care-planning meetings with patient interviews supported a novel understanding of what role patients had in relation to other actors and why. Focus groups were appropriate for exploring how health professionals experienced and approached the WMTY intervention. The interactions in focus group

discussions could generate rich data by encouraging participants to clarify individual and shared experiences, perspectives, and justifications related to patient participation (Barbour 2018; Kruger and Casey, 2015; Orvik et al. 2013). Documents were beneficial for examining the prescriptions for the WMTY intervention and justifications for patient participation. Table 3 provides an overview of the methodology of the papers that this thesis comprises.

**Table 3: Overview of the three papers**

	Paper 1	Paper 2	Paper 3
Aim	Examine the normative integration process	Development of a conceptual model	Concept development
Study design	Case study	Grounded theory	The stepwise-deductive inductive approach
Sources of data/methods	Documents from macro- and meso-level, direct observations, focus group interviews with health professionals	Focus group interviews with health professionals	Observations of meetings combined with individual patient interviews
Analysis	Deductive. Latent content analysis.	Inductive. Constructivist grounded theory.	Inductive-deductive. Stepwise-deductive induction.
Operationalization of goal-oriented care and integration	Goal-oriented care as a case across levels of health services. Normative integration.	Exploring health professionals' "main concern" when setting goals with patients. Interpersonal integration.	The patient's role and their interactions and experiences in care planning. Interpersonal integration.

## 2.4 Recruitment

### 2.4.1 Recruitment of the municipalities

Because implementation of the WMTY intervention was in an early phase in Norway, purposive sampling was appropriate. In purposive sampling, the researcher selects participants based on personal judgment about who will be most informative for the research question (Polit and Beck 2012). To identify municipalities that had implemented the intervention, I attended a regional learning network for improvement of integrated care pathways for older patients with multimorbidity ongoing from 2017 to 2019, in which

the WMTY intervention was central (see p. 36). I invited four of these municipalities to participate by contacting the municipal director for health and care services of each municipality by email. One municipality declined to participate because another research project was ongoing. The fourth municipality in this thesis was invited six months later. It had completed participation in a learning network and information available online indicated that the WMTY intervention was carried out in daily practice. The four municipalities had implemented the WMTY intervention 6–12 months prior to the start of the data collection for this thesis.

Two urban municipalities had 40,000 and 70,000 inhabitants, respectively, while two rural municipalities had 2,000–3,000 inhabitants. The four municipalities were all located in two counties in Western Norway. Four municipalities were considered enough to study goal-oriented care because each municipality included several settings: office for allocation of services, intermediate care unit, rehabilitation ward, nursing home, reablement services, and home care services. These settings also represent different stages of a care pathway after hospital stays.

#### *2.4.2 Recruitment of health professionals for the focus groups*

One focus group was conducted in each of the four municipalities. The sample of health professionals was purposive (Polit and Beck 2012). The sample represented a variety of occupations because care for patients with multimorbidity is multidisciplinary. Moreover, different clinical settings of a care pathway were included. One manager in each municipality recruited participants across wards. Hence, most of the health professionals were not recruited by their own ward manager. They were invited in person or by email to a focus group at their workplace. Twenty-seven persons were recruited; of these, three did not attend due to illness.

#### *2.4.3 Recruitment of patients to individual interviews and observation of meetings*

Patients were recruited by ward managers. The eligibility criteria were:

- Patients with two or more chronic diseases. This criterion did not specify whether the diseases were somatic or mental. However, in this care pathway, patients were mainly treated for somatic diseases.
- Patients should be included in the municipalities' care pathway for older patients with multimorbidity, in which the WMTY intervention was a component. Patients in this care pathway had been transferred from either hospital or an intermediate care unit, and the initial plan was to go home.
- Patients had newly emerged or changed needs for services and need for a care-planning meeting. In other words, they had functional decline.
- The data collection started by including patients aged 80 and over. Later, older patients under 80 years were also included in the study because the municipalities planned care similarly for patients under and over 80 years.

Exclusion criteria:

- Patients who were at the end-of-life-stage were excluded because they would receive advanced care planning, which differs from goal-oriented care.
- Patients who were unable to give or withdraw their consent to participate in the study. This included patients with dementia, delirium, and cognitive impairment.

The purposive sample of care-planning meetings within which the intervention was carried out represented different kinds of wards. Moreover, the meetings took place at different points in an integrated care pathway in the municipality; thus, they included meetings for patients newly transferred from hospital, meetings at a rehabilitation ward, and meetings after transfer home. The meetings were planned independently of this study. Most often, a nurse manager contacted me when they had a planned meeting and the patient, the patients' relatives, and health professionals had consented to participate in the study. In two of the municipalities, I did not initially obtain access to meetings to observe. One rural municipality said they had few eligible patients, and the other one did

not explain the reason. I called them several times, and after some months I was invited to observe their meetings.

## 2.5 Data collection and sample

Different types of data were collected simultaneously to gain an overview and understanding of the WMTY intervention. Two-thirds of the data was collected within 6 months, in autumn and winter of 2018–2019, and the rest during 2019. This allowed for an iterative process of data collection and analysis simultaneously; it also allowed me to ask follow-up questions for the analysis and clarify aspects I understood poorly.

### 2.5.1 Data collection in focus groups

The aim of the focus groups was to explore health professionals' experiences of interacting with older patients with multimorbidity. In accordance with grounded theory methodology, the interview guide was semi-structured and focused on actions and process (Charmaz 2014). Moreover, the interview guide was developed to capture a range of types of situations from health professionals' practices as well as their experiences. Questions were few (Krueger and Casey 2015). See the interview guide in Appendix 5.

Patient participation was used as a "sensitizing concept." This means that the concept of patient participation served as an initial but tentative idea, as a point of departure to facilitate the focus group discussions among health professionals (Charmaz 2014). The concept of patient participation did not define or limit how health professionals were invited to talk about their interactions with patients. I analyzed the data from the subsequent interview before carrying out the next one. During data collection, I found that the participants' descriptions of how they carried out the intervention aligned with the concept of collaborative goal setting (Vermunt et al. 2017). To increase credibility, the data analysis was based on that concept. During the analysis, theoretical sampling questions were added to the interview guide for subsequent focus groups (Charmaz 2014).

Each focus group had 5–7 participants (Table 4). The participants knew about one another, but most of them did not work in the same wards. In each focus group, 2–3 of the participants attended the focus group because they were implementing the intervention. Others participated to represent different occupations, and the rest simply because they were at work the day the focus group was carried out.

**Table 4: Health professionals in each of the four focus groups**

Participants in the focus groups	Duration
Nurse working as case manager at office for allocation of services (advanced practice nurse) Nurse in home care services Occupational therapist at rehabilitation ward Nurse manager at rehabilitation ward Physiotherapist in reablement services	2 hours
Nurse manager at home care services and residential care (student in advanced practice nursing) Nurse in home care services (further education in oncology nursing) Nurse manager at short-term and dementia ward (further education in Older Patients and Aging) Nurse manager at a mixed short-/long-term ward (further education in nursing) Physiotherapist in the municipality, in nursing homes and patients' homes Nurse at nursing home Auxiliary nurse at home care services	1 hour and 30 minutes
Nurse manager home care services (advanced practice nurse) Nurse at short-term ward Auxiliary nurse at home care services Physiotherapist in home care services and nursing homes Nurse in home care services Staff member without health education, home care services (background in social services)	1 hour and 30 minutes
Occupational therapist, patient care pathway coordinator (further education in rehabilitation) Auxiliary nurse at intermediate care unit Nurse at rehabilitation ward Physiotherapist at rehabilitation ward Physician at an intermediate care unit Nurse at an intermediate care unit	1 hour



The focus groups took place without interruptions in meeting rooms within participants' workplaces. They lasted an average of 90 minutes and were audio-recorded. During the discussions I asked questions directly of participants who were less vocal to elicit their views (Patton 2015). Either RK or MS served as co-moderator and asked clarifying questions at the end of the interviews. Afterwards, I and the co-moderator discussed what we observed about the interaction in the group; for example, the (un)shared language and beliefs among participants, their tone of voice, engagement, and their roles in the group (Belzile and Öberg 2012). We also discussed how they depicted WMTY and how to interpret this within their municipal context. I wrote field notes after each focus group.

#### *2.5.2 Data collection of documents*

The sampling of documents was purposive; they were prescriptive for the WMTY intervention in service delivery for older patients. All documents related to this topic used in the study settings in 2019 were collected.

- Documents from the macro-level of health services included a white paper and a guideline.
- Documents from the meso-level included public municipal strategy plans, WMTY tools, and care pathway checklists.

Documents can be perceived as more than “passive” resources. Documents play a part in social configurations. In social settings, they can acquire functions as agents, like decision-makers, experts, and illustrators (Prior 2010). For example, white papers are, among other things, attempts to govern meanings about what should be done (Pollitt 2013). In this way, documents are illustrative for the concept of normative integration proposed by Singer and colleagues (2020).

The macro-level white paper and guideline were retrieved from the internet. These were designed to be used in the lower levels of the health system as guidance and normative recommendations for the WMTY intervention. The governmental white paper “A full life -

all your life A Quality Reform for Older Persons” describes how WMTY should form the basis of service delivery (Norwegian Ministry of Health and Care Services 2018). After reading the whole text, the chapters describing patient participation were extracted: Chapter 1 (“Goals and target group”), Chapter 7 (“Health care”), and Chapter 8 (“Coherence”). The clinical guideline “for follow-up of persons with complex needs” is the first Norwegian guideline describing integrated care for older patients with multimorbidity (Norwegian Directorate of Health 2018a). Parts of the guideline were excluded because they pertained to younger patients and work tasks beyond the scope of this thesis.

The meso-level municipal strategy documents were collected from the municipalities’ public web pages in August 2019 to examine whether the WMTY intervention was included in prevailing municipal policy. The search terms used to identify these documents were primarily care pathways for older patients with multimorbidity (in Norwegian: *helhetlige pasientforløp, eldre personer, multisykdom, store og sammensatte behov*), patient participation (at the individual level) (*bruker-, eller pasientmedvirkning*) and the phrase “What matters to you?” (“*Hva er viktig for deg?*”). All relevant text in strategy documents amounted to 500–1,000 words per municipality. These webpages are not referred to here, as doing so would identify the municipalities and study participants. The care pathway checklists and tools to be used by health professionals to enable the WMTY intervention were developed at organizational level. These documents were identified by, and collected from, health professionals in each municipality, either in or right after the focus groups or observations of meetings. Health professionals explained how and to what extent they were used in clinical practice. These were collected between October 2018 and December 2019.

### *2.5.3 Data collection by observations of care-planning meetings*

Observations of the ten care-planning meetings focused on how the WMTY intervention was carried out. (The WMTY intervention was described on p. 22). The observations were

made between October 2018 and December 2019. Short site visits can be used when observations are focused on certain aspects of a practice (Patton 2015), and WMTY is one component of care-planning meetings. I developed the observation guide, which covered observations of the setting (place, meeting agenda, WMTY tools), interactions and communication through the WMTY conversation, and patient participation (observation guide Appendix 6).

The observer role can be on a continuum from participant to spectator (Patton 2015). I aimed to adopt a spectator-observer role by not talking during the meetings. I sat at the table with the other participants and engaged in small talk before and after the meetings. However, in four of the meetings I assume my role was more salient because only the patient, the nurse, and I were present. They included me in small talk a few times during the meeting. I wore a white blouse in order not to stand out too much from the health professionals. I disclosed my role as that of a researcher studying WMTY without sharing the content of the observation guide. To reduce my influence on the participants, I jotted down keywords in the observation guide during the meetings and wrote longer field notes after each meeting. I aimed to keep the field notes descriptive, recording my own interpretations in a separate column (Patton 2015).

The meetings were audio-recorded with a Dictaphone. The last meeting was not recorded at the request of two of the health professionals. I did not ask them to justify their preference, as participation in the study was intended to be voluntary. Instead, I wrote thorough notes during the observation and wrote citations about WMTY. The meeting agendas were similar across settings; therefore, ten meetings were deemed sufficient to assess how the intervention was carried out, especially because the observations were combined with other data sources in the analysis to explore the matter in depth.

#### *2.5.4 Data collection of individual interviews with patients*

The aim of the interviews was to explore patients' experiences and roles within the care-planning meetings. I carried out the interviews immediately after each meeting. The semi-structured interview guide (Brinkmann 2018) covered the topics of the patient's experience of the current disease episode, their experience of being asked WMTY within the current disease episode, their participation in the care-planning meetings, and what mattered to them (Appendix 7). Neither patients' relatives nor health professionals were present at the interviews. The interviews lasted for 36 min. on average, and the length was adjusted to the energy level of each patient. I audio-recorded and transcribed the interviews verbatim. One of the interviews was not audio-recorded because I made a mistake in the use of the Dictaphone. This interview was repeated by telephone three weeks later and audio-recorded. This interview was short but could be supported by my field notes from the first interview.

The meetings took place at different stages of a care pathway: right after hospital discharge, at the middle of a stay in a rehabilitation ward, or right before/after transfer to home. Eight of the patients had been hospitalized during the current disease episode. The main health problem leading to the current contact with health services was intertwined with other diagnoses. The ten patients' mean age was 88 years. All patients had functional decline, and none could walk without aids or help. Two of the patients had a salient mental diagnosis. More information about patients is provided in Table 5.

#### **Table 5: Characteristics of the ten care-planning meetings and the patients involved**

<b>Patient's gender, age</b>	<b>Patient's main problem, number of diagnoses</b>	<b>Kind of ward</b>	<b>Participants in the care-planning meeting (average duration 41 minutes)</b>	<b>Place and duration for the patient interview</b>
P#1 Female, 86 years	Fractured arm. >2 diagnoses.	Start of stay at rehabilitation/ intermediate care unit, city municipality.	Patient and a nurse. 25 minutes.	Meeting room at the ward. 51 minutes.
P#2 Female, 96 years	Chest pains and abdominal pain. >4 diagnoses.	Start of stay at rehabilitation/ intermediate care unit, city municipality.	Patient and a nurse. 19 minutes.	Patient's room at the ward, patient lying in bed. 35 minutes.
P#3 Female, 97 years	Fall, fractured neck of femur, with infection. >5 diagnoses.	End of stay at rehabilitation ward, city municipality.	Patient, case manager from office handling allocation of services, physiotherapist, nurse, home care nurse, and daughter. Three nursing students observed the meeting. 47 minutes.	Patient's room at the ward. 1h and 50 minutes.
P#4 Female, 98 years	Several falls assumed to be caused by orthostatic hypotension. >2 diagnoses.	End of stay at rehabilitation ward, city municipality.	Patient, case manager from office handling allocation of services, nurse at the ward, home care nurse, daughter, and adult granddaughter. 38.5 minutes.	Meeting room at the ward. 32 minutes.
P#5 Female, 62 years	Pneumonia and other pulmonary disease. >5 diagnoses.	Middle of stay at intermediate care unit, city municipality.	Patient, husband, case manager from office handling allocation of services, and nurse from the ward. One nursing student observed the meeting. 25 minutes.	Meeting room and at the end, at patient's room at the ward. 31 minutes.
P#6 Female, 91 years	Weakened by cumulative effect of multiple conditions. >5 diagnoses.	Middle of stay at rehabilitation ward, city municipality.	Patient, case manager from office handling allocation of services, home care nurse, and ward nurse. Daughter and two sons. 50 minutes.	Patients room, patient lying in the bed. 15 minutes.
P#7 Male, 94 years	Functional decline and emerging needs for home care services. >5 diagnoses.	Meeting at patient's home before short-term stay at nursing home, rural municipality.	Patient, wife, and nurse in home care services. 1 hour and 5 minutes.	Ca 20 min interview not audio-recorded, repeated by tele-phone, 10 minutes.
P#8 Female, 96 years	Syncope. >2 diagnoses.	Meeting at patient's home, right after stay in intermediate care	Patient and nurse in home care services. 21 minutes.	Patient's home, 25 minutes.

		unit, rural municipality.		
P#9 Female, 86 years	Hip surgery. >5 diagnoses.	Middle of stay at short-term ward, rural municipality.	The patient did not wish to participate in the meeting. Four daughters, head nurse at care home, physiotherapist, and nurse. 59 minutes.	Patient's room. 20 minutes.
P#10 Male, 75 years	Fractured neck of femur. >4 diagnoses.	End of stay at short-term ward, rural municipality.	Patient, head nurse in home care services, physician, physiotherapist, mental health nurse, case manager, daughter, son, and nurse from home care services. 1 hour.	At the ward, 33 minutes.

In addition to observing meetings, I learned about the field by being present before and after the meetings and focus groups. Health professionals showed me routines such as WMTY in the documentation system and on whiteboards in their ward office as well as WMTY materials. Furthermore, I attended 6 full-day seminars of a learning network. This allowed for conversations with health professionals, managers, and other stakeholders at different levels of health services to obtain insight into the WMTY intervention. Finally, the thesis was informed by my experience of working as a nurse at a hospital during the period when this improvement of integrated care for older patients with multimorbidity started. These activities broadened my understanding of the intervention and its context.

I transcribed the audio-recorded meetings and interviews verbatim. In the transcriptions, I also recorded moments of silence, sighs, laughter, and happenings in the room that I had captured in the observation guide.

#### *2.5.5 Saturation of data*

In the case study of normative integration (Paper 1), saturation was assessed by how justifications for patient participation in the data could make visible whether each of the seven institutional logics appeared weakly or strongly (Thornton, Ocasio and Lounsbury 2012). For the focus groups (Paper 2), data saturation was obtained by categorical

variation (Charmaz 2014). Health professionals described of a range of situations that made variety in the categories occur, and theoretical sampling questions were added to the interview guide. The observed meetings and patient interviews (Paper 3) generated rich data about the patient participation interactions. The research questions could be answered through the developed categories and concepts.

## 2.6 Analysis

The thesis design was emergent, and during data collection I decided to use parts of the data twice, in two papers with different perspectives. The data from focus groups was rich, containing both descriptions of how health professionals carried out the intervention for this patient group (Paper 2) and discussions of situations that made explicit their justifications for patient participation (e.g., institutional logics, Paper 1). The data from the observed meetings informed one analysis about institutional logics between levels of health services (normative integration), while the other analysis emphasized the patient perspective and interactions (interpersonal integration).

### 2.6.1 *The case study (Paper 1): Content analysis*

The case of normative integration across levels of health services was investigated with the following sources of data: observations of ten care-planning meetings, four focus groups, and the documents describing the WMTY intervention. The case and its boundaries were defined based on theoretical propositions (Yin 2014)—specifically, institutional logics and normative integration—as explained in the conceptual framework (on page 29, and in greater detail in Paper 1. The structure of the deductive content analysis was operationalized by the seven institutional logics (Thornton, Ocasio and Lounsbury 2012) at the macro-, meso-, and micro-level of the health services. Here, we applied an analytical matrix (Elo and Kyngäs 2008) to develop the categories of institutional logics at the various levels of health services. These were analyzed using latent content analysis, in which the researcher seeks to interpret the underlying meaning of the text: what the text is talking about (Bengtsson 2016; Graneheim and Lundman

2004). Here, the institutional logics and their associated justifications for patient participation were regarded as latent content.

The four steps of the analysis are: decontextualization, recontextualization, categorization and compilation (Bengtsson 2016). The macro-, meso-, and micro- level were analyzed separately before the whole of the case was examined and the three levels compared (Yin 2014). It was essential throughout this analysis to interpret the whole of the texts to understand the case. In the decontextualization phase, normative justifications for patient participation guided initial coding (Bengtsson 2016). The concepts of institutional logics and patient participation were connected through regarding the justifications as representing different institutional logics (Thornton, Ocasio and Lounsbury 2012; Beedholm and Fredriksen 2019). I and RK separately coded the data and regularly discussed the ongoing analysis with each other and the co-authors. Text that could be coded to two logics were discussed to reach consensus. In the recontextualization phase, meaning units and text extracts were inserted in tables. Text not relevant to the research aim was excluded. In the categorization phase, properties of the seven institutional logics were identified along with the constellations constituting them at each level (Goodrick and Reay 2011; Waldorff, Reay and Goodrick 2013). Theoretical concepts could enrich interpretations. At the micro-level, we examined how active patients were expected to be in goal setting—that is, the levels of patient participation (Vermunt et al. 2017; Halabi et al. 2020; Beedholm and Fredriksen 2019). In the compilation phase, we examined how the constellation of logics at macro-, meso-, and micro-level was either facilitating or constraining patient participation. Finally, to assess normative integration, we compared the constellation of logics across these levels (Singer et al, 2020).

### *2.6.2 Analysis in Papers 2 and 3*

Grounded theory methodology was developed by Glaser and Strauss (1967); Charmaz (2014) subsequently developed a constructivist version. The epistemological foundation is constructivist rather than objectivist, viewing the analysis as located in the time, place,



and situation of inquiry (Charmaz 2014, 236). Grounded theory was suitable to study interpersonal integration because it explores social processes of actions and interactions and explains how people resolve their central concerns (Charmaz 2014; Glaser and Strauss 1967).

Grounded theory analysis aims to develop theories grounded in real-world observations. Theory can be developed at a formal level, which is generic across areas. This study takes place rather at the substantive level, which means that the developed concept applies to a delimited problem in a particular area (Charmaz 2014; Glaser and Strauss 1967). Theory identifies relationships between concepts. Concepts are lower-order components of theories (Charmaz 2014; Tjora 2019). This thesis develops concepts rather than theory. A concept is “an abstraction inferred from observation of behaviors, situations, or characteristics” (Polit and Beck 2012, 722). The analysis generates an imaginative theoretical interpretation of the studied phenomenon (Charmaz 2014, 231). This process is inductive, and a bit abductive in the sense that the concepts add something new to the data that they do not already contain and that does not already exist as a concept (Reichert 2007, 225; Tjora 2019).

#### *The focus group study of health professionals (Paper 2): Grounded theory analysis*

Grounded theory was chosen because the literature lacked concepts about health professionals' approaches to setting goals with older patients. In grounded theory, inductive data is used to construct abstract analytic categories through an iterative process. The analysis had four steps; initial coding, focused coding, development of categories by the constant comparison method, and theoretical coding of the relation between categories (Charmaz 2014; Thornberg and Charmaz 2014). Patient participation was used as a sensitizing concept (Charmaz 2014; Blumer 1969), serving as a point of departure for the analysis of health professionals' interactions with patients without defining or limiting how the data would be coded. Later, I found that the participants' descriptions aligned more with the concept of collaborative goal setting.

In the initial coding, small units of the transcripts were coded to explore health professionals' actions and define what happened in the data (Charmaz 2014). This resulted in approximately 400 initial codes. Verbs and words from the text were used to label the codes. Then, in focused coding, I merged similar initial codes. Frequent and significant codes were refined to focused codes that could synthesize the data. To develop ideas and hunches about how to interpret the data, I wrote informal analytic notes ("memos") throughout the analysis process (Charmaz 2014). By the constant comparison method, the focused codes were tested against all the data to develop categories with subcategories (Charmaz 2014). The categories related mainly to characteristics of patients' situation, how health professionals initiated collaboration with patients, and how the municipal context influenced their actions. Through theoretical coding (Thornberg and Charmaz 2014), categories that related to one another and accounted for a large amount of the data—that is, four categories and one core category that represented the main concern of health professionals when setting goals with patients—were included in a conceptual model. Three co-authors discussed each stage of the analysis for Papers 2 and 3 to broaden the frame of reference and to reach a consensus on the interpretation of the data.

*Observations of meetings and patient interviews (Paper 3): Stepwise-deductive induction*

Stepwise-deductive induction is based on grounded theory (Tjora 2019). Because the existing literature is unclear about why some older patients were passive in decision-making, this method of analyzing the interactions in care-planning meetings and developing a concept about them could generate new understanding. This method was chosen because it aims to elaborate new ideas from empirical data (Tjora 2019). Moreover, the analysis is more linear than in grounded theory because the researcher does not move back and forth between all stages of the analysis; the coding process is iterative only between adjacent stages. Thus, theoretical sampling is not emphasized as it is in grounded theory (Tjora 2019, 5).

The data included in this analysis were transcripts from the patient interviews and the care-planning meetings. The data from the observation guide and the field notes were not coded but provided understanding of how WMTY were carried out and of the context. The analysis begins inductively and subsequently draws on existing theory. The stages are 1) empirical close coding, 2) grouping codes to subcategories, 3) merging subcategories with theory, and 4) concept development. Elements in the data that trigger analytical ideas—so-called “empirical-analytical reference points”—are recorded in memos (Tjora 2019).

I carried out the analysis. First, I read the transcripts several times to obtain an overview. Small sections of text were labeled using words and phrases that stood out in the material. This resulted in 530 inductive codes. Second, codes were grouped based on the level of coherence in each group. The co-authors had read the transcripts. We discussed these groups and how to interpret the emerging patterns as well as discussing the different roles of participants. Third, the code groups, or categories, were merged with elements from game theory. Game theory was considered relevant because games can serve as a metaphor through which to understand patient participation (Allen, Griffiths and Lyne 2004; Tarrant, Stokes and Colman 2004; Colman 1995). The interaction patterns in the data corresponded to three kinds of games found in theory. The elements of theory that were included were interactions within the three types of games, the roles of players, and how elements of chance/randomness could influence the games. This is described in more detailed in Paper 3 and the accompanying Additional File 2. The categories were developed by moving back and forth between the empirical data and the insights of game theory.

During the last step of the analysis, the conceptualization, we chose to “zoom in” on certain categories (Halkier 2011) that related to uncertainty in decision-making. We examined how the informants assessed uncertainty in care planning by looking for statements reflecting beliefs about whether and how one could plan care and the

likelihood that these plans would come to fruition. Finally, we examined levels of patient participation as described in the conceptual framework (p. 32).

#### *Software in the analysis*

The three analyses were supported by the software for qualitative data analysis NVivo 12 Pro (Melbourne, Australia: QSR International Pty Ltd., 2018). However, the first, inductive stage of analysis generated 400-500 codes that first were grouped in the word processing program Microsoft Word.

### 2.7 Ethical considerations

In health services research, the protection of human rights is essential. This thesis attended to the ethical principles for research articulated in The Declaration of Helsinki (World Medical Association 2013).

The autonomy of the health professionals, patients, and relatives who participated was considered. To obtain informed consent before the data collection started, participants received information about the study both orally and in writing (see Appendices 3 and 4). Participation was voluntary; I did not try to convince anyone to participate. Participants were assured that they could withdraw from the study at any time without duty to explain why. Patients were ensured they would receive the same treatment from health services regardless of their participation in the study. Persons who recruited participants received a written description of how to do so and understood that participation should be voluntary and informed. In the non-participant observations, I disclosed my role as a researcher and the purpose of the thesis. Before observation of one of the meetings, two of the health professionals expressed a wish that the meeting not be audio-recorded. To maintain the voluntary nature of their participation, this wish was respected without asking them to justify why.

Precautions to protect privacy and the confidentiality of the information collected about participants is important (World Medical Association 2013). The Regional Committee for Medical and Health Research Ethics waived the need for approval of the studies because they were not regulated by the act of health research (reference number 2018/852/REC central, see Appendix 2). The Norwegian Center for Research Data approved that appropriate steps to protect personal information of study participants were taken (project number 60524, see Appendix 1). The written consent forms as well as my field notes were stored in a locked cabinet at the university, the audio-recorded files were encoded, and all participants and municipalities were anonymized during transcription by me. The audio and text files were stored safely in the electronic area of the university to protect the anonymity of participants throughout the research process. In reporting the results, I have provided little information about participants and municipalities to preserve their anonymity.

Vulnerable groups should not be harmed in research (World Medical Association 2013). The patients studied were in a vulnerable situation because they were dependent on health services and the health professionals who asked them to participate in the study. Hence, patients were ensured they would receive the same treatment regardless of their participation. Health professionals were not present at the interviews, and patients were ensured that their views would not be shared at the ward. Moreover, the role of patients could be vulnerable in relation to the researcher. To minimize the potential burden of participating in research during illness, the length of the interviews was adjusted to patients' level of tiredness. I was careful not to ask for more information than patients wanted to share or than was necessary to answer the research questions (e.g., I did not ask for details about their diseases). This research could benefit older patients with multimorbidity, as knowledge about their perspectives can be used in future health service delivery.

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## 2.8 The researcher's role and reflexivity

Reflexivity concerns the awareness of how the researcher influences the research process. In qualitative studies, the researcher is the primary research instrument. Thus, the researcher's background, values, assumptions, and biases need to be identified to allow the reader to assess how he or she might have influenced the generation of results (Malterud 2001; Creswell 2014).

I have worked as a nurse for older patients with multimorbidity at a medical hospital ward. One of my work tasks was similar to the topic of this study: care planning before the patient's hospital discharge. I wrote reflective notes at the start of this thesis to be aware of my experiences and preconceptions (Polit and Beck 2012). My preconceptions included, firstly, an assumption that patients generally participated little in care-planning meetings. I supposed that health professionals' opinions, the routines of the health services, and limitations on the allocation of resources would be given precedence over patients' preferences. Secondly, I was used to seeing older patients with severe disease and consequently assumed that most patients in a care pathway wanted to stay in an institution rather than going home. Thirdly, the literature I had read depicted older patients as frail, with complex needs, and with reduced capacity to participate actively. In sum, I questioned how much power health professionals and patients would or should have to formulate goals that would change the course of health service delivery. During my work on this thesis, I increasingly came to value patient participation, perhaps because it is an ideal in the integrated care literature.

The values of the researcher and the context influence knowledge construction (Lincoln and Guba 2013, 41). What researchers see, and do not see, depends on their values (Charmaz 2014). To enhance the credibility of the data analysis, the group of co-authors

discussed the interpretations at each stage. The co-authors had different experiences and held different academic backgrounds. However, we had in common the fact that we are Norwegian academics. Patient participation is valued in our society, and it could be a value among academic researchers to problematize the practices within health services. Other researchers might interpret the same data differently.

On the other hand, there were ways in which my experience as a nurse was advantageous to data collection and analysis. I am used to interacting with this patient group, which made communication in the patient interviews easier as well as helping me to adjust the length of the interviews to patients' levels of fatigue. My background enhanced my understanding of many of the situations that the health professionals discussed in the interviews; what is more, I could think of alternative courses of action which were not discussed. My "insider" understanding of the routines of the care pathway, the context, and health professionals' roles was helpful. However, I had to balance these advantages with the need not to identify myself to the participants and to avoid letting my preconceptions guide the data collection or the analysis.

### 3. Results

This thesis was about goal-oriented, integrated care for individual older patients with multimorbidity in Norwegian primary health care. The aim was to explore normative and interpersonal integration by investigating how patient participation emerged when the WMTY intervention was carried out.

#### OVERVIEW OF RESULTS FROM PAPERS 1–3.

##### 3.1 Normative integration of the levels of health services (Paper 1)

Oksavik, Jannike D, Turid Aarseth, Marit Solbjør, Ralf Kirchhoff. 2021. 'What matters to you?': normative integration of an intervention to promote participation of older patients with multi-morbidity – a qualitative case study. *BMC Health Services Research*, 21(117). doi:10.1186/s12913-021-06106-y

This paper investigated normative integration of the WMTY intervention between levels of health services by exploring how patient participation was justified and materialized in clinical practice. Different constellations of institutional logics were salient at the macro-, meso-, and micro-level of health services, respectively. Within the macro-level documents, seven institutional logics justified patients' freedom of choice, person-centered care, and individualization of service delivery. At meso-level, the operationalization of the intervention into tools for clinical practice was dominated by a state logic valuing equal services for all patients and a medical professional logic in which patient participation meant deciding how to maintain patients' physical abilities. At micro-level, the discussions of health professionals and the observations of care-planning meetings indicated that their practices were dictated by a mix of the professional logic and the state logic found at meso-level with a corporate logic prioritizing cost-efficient service delivery. The number of institutional logics in play was reduced downwards through the three levels, and the justifications for patient participation within the WMTY intervention appeared to shift from ones that placed a value on individualization to ones that favored standardization.



### 3.2 Interpersonal integration between health professionals and patients (Papers 2 and 3)

These two papers report divergent perceptions between health professionals and patients about how to plan care. Two processes were found: “sharing responsibility” and “games of uncertainty.” These were characterized by different patterns of interactions and varying levels of patient participation.

#### *Health professionals’ perspectives: sharing responsibility with patients (Paper 2)*

Oksavik, Jannike D, Ralf Kirchhoff, Maren KR Sogstad, Marit Solbjør. 2020. Sharing responsibility: municipal health professionals’ approaches to goal setting with older patients with multi-morbidity – a grounded theory study. *BMC Health Services Research*, 20(141). doi:10.1186/s12913-020-4983-3

Health professionals’ experiences of interacting with older patients with multi-morbidity in collaborative goal setting were explored. Health professionals attempted to varying extents to share responsibility for goal setting with patients. To do so, they took one of four approaches to goal setting with individual patients: motivating for goals, vicariously setting goals, negotiating goals, or specifying goals. “Motivating for goals” entailed that they educated patients who were reluctant to set goals. Patients’ capacity or willingness to set goals could be reduced due to old age, illness, or level of knowledge about the health system. The approach of “vicariously setting goals” was used with patients who did not express or take responsibility for goals because they were in a process of adaptation to disease or had such symptoms as cognitive impairment or exhaustion. “Negotiating goals” was an approach taken to handling disagreements with patients, and often relatives, who expected to receive more services than usual care. Some patients seemed passive or to have unrealistic goals for improving health. “Specifying goals” was a collaboration. Patients currently being treated for one condition set sub-goals to increase health. Patients with complex diseases prioritized one goal to maintain health (Paper 2).

#### *Patients’ perspectives: varying levels of uncertainty (Paper 3)*

Oksavik, Jannike D, Marit Solbjør, Ralf Kirchhoff, Maren KR Sogstad. 2021. Games of uncertainty: the participation of older patients with multimorbidity in care planning meetings – a qualitative study. *BMC Geriatrics*, 21(242). doi:10.1186/s12877-021-02184-z

The study explored the experiences of patient participation and the interactions involved for older patients with multimorbidity in care-planning meetings. A perception of uncertainty to varying extent characterized patients' experiences as well as the interactions of participants in care planning. This uncertainty concerned the unknown course of disease and how to plan service delivery. Viewed through the lens of game theory, uncertainty of this kind is represented as an imaginary player, called "Nature". Nature participated in care-planning meetings and was associated with patients taking different roles. The varying salience of Nature in decision-making was associated with three kinds of interaction patterns, or games. First, in the game of chance, patients acted as if what would happen in the care pathway was random and uncontrollable. They were overpowered by the opponent Nature and passive in decision-making. Second, in the competitive game, players positioned themselves on two opposing sides. One side assessed Nature as a threat, while the other side was unaware of Nature. Hence, negotiations took place about whether and how to account for uncertainty in decisions about future care. The level of patient participation varied. Third, in the coordination game, all players were aligned, either as teammates against Nature or in being undisturbed by Nature's presence. The level of patient participation was high.

### 3.3 Synthesis of results

The three papers together illuminate integration within goal-oriented, integrated care. The study of normative integration indicated that too few institutional logics were shared vertically across levels of health services for the normative justifications to align. Interpersonal integration was found in some of the interaction patterns, but not across all the care-planning meetings. Three processes appeared: different justifications for patient participation (Paper 1), sharing responsibility (Paper 2), and games of uncertainty (Paper 3). Table 6 sums up these three processes and the associated patterns of interaction.

#### **Table 6: Processes and interactions within the WMTY intervention**

## The care planning intervention “What matters to you?”

NORMATIVE INTEGRATION	INTERPERSONAL INTEGRATION	
<p style="text-align: center;"><b>Different justifications for patient participation</b></p> <p>Multiple institutional logics representing individualization</p> <p>Three institutional logics representing standardization</p>	<p style="text-align: center;"><b>Sharing responsibility</b></p> <p style="text-align: center;">Specifying goals</p> <p style="text-align: center;">Motivating for goals</p> <p style="text-align: center;">Negotiating goals</p> <p style="text-align: center;">Vicariously setting goals</p>	<p style="text-align: center;"><b>Games of uncertainty</b></p> <p style="text-align: center;">Collaborative game</p> <p style="text-align: center;">Competitive game</p> <p style="text-align: center;">Game of chance</p>

The patterns of interactions listed in each column of the table represent different levels of patient participation. The interactions at the top (i.e., multiple institutional logics representing individualization, the process of specifying goals, and the collaborative game) all represent a high level of patient participation. The interactions at the bottom of each column represent low levels of patient participation.

Normative and interpersonal integration were not fully achieved. There were different goal-orientations among actors—that is, different justifications and perceptions about what could happen in care planning and how. The principle of standardization that operated at micro-level (Paper 1) can be associated with how health professionals attempted to share responsibility for health service delivery with patients (Paper 2). Again, this can be challenging given some patients’ perceptions of uncertainty about how they could contribute to their rehabilitation process (Paper 3).

The justifications for patient participation in goal-oriented, integrated care and the levels at which participation occurred varied. Variation in patient participation in goal setting occurred in an interplay between the conditions of the older patients with multimorbidity and the justifications for patient participation held by health professionals, health services in the municipalities, and health policy, respectively. However, sometimes the goals of patients, health professionals, and the context were aligned.

## 4. Discussion

This chapter first discusses the methodology and the trustworthiness of this thesis. This is followed by a discussion of the main results and their implications.

### 4.1 Methodological discussion

There are no unified, set criteria to assess the rigor of qualitative research. The construct of trustworthiness established by Lincoln and Guba is consistent with the assumptions of the constructivist paradigm and is well known (Schwandt, Lincoln and Guba 2007; Patton 2015). Trustworthiness can be assessed by four interrelated quality criteria, which are analogues to conventional criteria: credibility (internal validity), transferability (external validity), dependability (reliability), and confirmability (objectivity) (Schwandt, Lincoln and Guba 2007). These criteria for trustworthiness will be used to discuss the strengths and limitations of this thesis.

#### 4.1.1 *Design of the studies*

Inclusion of multiple settings and wards enhances transferability to other care pathways. In these studies, method triangulation enhanced credibility in exploring goal-oriented, integrated care. However, there is an inherent limitation involved in exploring patient participation without including patients as co-researchers, which is recommended as well as applicable to this patient group (Shippee et al. 2015; Markle-Reid et al. 2021). I learned this after the data collection started and assessed that the level of patient participation would be low if they were included late in the research process.

#### 4.1.2 *Data collection*

The point of time of data collection is a limitation because the WMTY intervention was implemented 6–12 months prior to the start of data collection, while it is recommended to carry out research after 12 months (Kirst et al. 2017). One possible explanation for my limited access to meetings in two of the municipalities at first contact could be that they first wanted to work in WMTY in their practices. The results of this thesis can be viewed as

a snapshot in an ongoing implementation process. How the WMTY intervention emerges in practice may change over time. The time frame of this research project did not allow for longitudinal data collection, which could have enhanced the dependability. However, I enhanced the credibility of the analysis by engaging in the field long enough to understand the context and to be confident in the results.

The data collection methods have some drawbacks. A bias in observations is possible, in that participants can behave differently when they know they are observed: “The Hawthorne effect” (Morgan et al. 2017). For example, persons who disagreed in the care-planning meetings might hesitate to disclose their views. Furthermore, field notes from observations are influenced and limited by what the observer chooses to focus on (Morgan et al. 2017). How much one can observe simultaneously is also limited. The audio-recordings mitigated this problem by allowing me to focus on what was happening in the room and the observation guide. The audio-recordings also allowed the co-authors to assess and interpret the material even though they were not present, reducing researcher bias.

Self-report qualitative methods are subject to participant reporting problems. A power imbalance between participants can circumscribe participants from disclosing their opinions (Barbour 2018; Morgan et al. 2017; Patton 2015). In each of the focus groups, some health professionals also were nurse managers or knowledgeable about the WMTY intervention because of participation in a learning networks for improvement of care pathways. Regarding the patient interviews, it is likely that some patients found it difficult to criticize health service delivery during treatment. Another weakness, applicable to two of the patient interviews in particular, is their short duration due to the tiredness of patients, which hampered an in-depth exploration of those patients’ experiences. On the other hand, the interviews were close in time to patients’ participation experiences, making it easier for patients to remember what had happened (Paper 3). The patient interviews were combined with insights from observations. The dependability was

increased by reinforcing the weaknesses of each separate method using triangulation. Observation, for example, allows researchers to see what people do rather than what they say they do (Morgan et al. 2017; Patton 2015).

For the results related to the experiences of patients (Paper 3), it may be a limitation that one patient was 62 years old, when “older” is defined as 65 and above. Her age was detected at the end of the interview. However, she was not excluded because her experiences were in line with those of other patients, she was handled with the same routines as the older ones, and she had several diseases and functional decline. She was an information-rich informant, having had several stays in the ward the prior year. However, I do acknowledge that I could have overlooked the fact that her case may differ in some points, which could be a threat to the credibility (in Paper 3) of my analysis of older patients’ views.

#### *4.1.3 The sample*

Purposive sampling of health professionals reduces transferability to others working in this context. Firstly, 2–3 of the participants in each focus group were involved in implementation of the WMTY intervention. They could have been more engaged in WMTY than others in their municipalities. However, including information-rich informants was necessary in the early implementation phase of the WMTY intervention; a random sample probably would have provided less information. Secondly, health professionals in a care pathway context can value physical rehabilitation and seek to share responsibility with patients more than in, for example, long-term wards. However, many wards were involved in the observed care-planning meetings, which included a range of views.

In the sample of patients, those with cognitive impairment, in an end-of-life phase, and in long-term wards were excluded. Moreover, only two were men. The inclusion of more men could have yielded more agreement between health professionals and patients on goals for the care pathway (Paper 3), as men tend to have a higher wish to live

independently than women (Meijering 2021). No immigrants participated. Barriers in service delivery exist for this group (Appoh, Felix and Peterson 2020). The results are not transferable to all older patients with multimorbidity. Even though my aim was in-depth understanding—a goal which justifies a small sample size—more than ten patients (in Paper 3) would have provided a greater understanding of the extent to which uncertainty and patient participation are connected. Furthermore, I had no opportunity to choose patients; they were recruited by health professionals. There is a risk that the recruiters might have excluded patients with whom they (for example) perceived collaboration to be difficult (Paper 1 and 3). Health professionals' descriptions of goal setting with this patient group (Paper 2) are more transferable because health professionals described their practices in working with the types of patients that were excluded from this thesis.

#### *4.1.4 Analysis*

Credibility deals with how well the categories cover the data (Graneheim and Lundman 2004). The constant comparison method in grounded theory to some extent ensures confirmability, because the core category must explain a large amount of the data (Charmaz 2014). To enhance dependability, I returned to the transcripts several times throughout the analysis process. After several weeks, I evaluated whether the results were in accordance with the data (Elo et al. 2014). Nonetheless, the constructivist research paradigm as well as grounded theory have been criticized for generating subjective results, which some would regard as a threat to confirmability (Schwandt, Lincoln and Guba 2007). I acknowledge that, particularly in the two inductive studies (Paper 2 and 3), other researchers could arrive at different categories. For example, other researchers would probably not associate the patient experience of uncertainty with “Nature” from game theory, perhaps exploring other theories instead. In the perspective of constructivism, multiple interpretations are possible. Moreover, concepts are modifiable and open for reconstruction (Charmaz 2014; Guba and Lincoln 1994). The overall results of the thesis are in line with previous research.

To increase the confirmability of the results, I wrote about my preconceptions at the start of the study and later compared these to the results. I found a similarity in how health professionals' disease-oriented focus as well as limited resources within health services may circumscribe patient participation. Hence, I compared the results to the literature and discussed with co-authors, research groups, and health professionals in the field, to determine whether my preconceptions had influenced the results. Three co-authors read the transcripts of the interviews and meetings and discussed how well the categories covered the transcripts. The co-authors enhanced confidence in the interpretations. We agreed that relevant data were included.

However, because multiple interpretations are possible within the constructivist paradigm, discussion as a means of enhancing credible findings among co-researchers and participants is questionable (Graneheim and Lundman 2004). Hence, the intent of dialogue among co-authors and neutral colleagues for the inductive analyses was not to verify the labeling and sorting of the data but rather to determine whether multiple researchers would agree with the results (Graneheim and Lundman 2004). For the analysis of institutional logics (Paper 1), a co-author and I coded the data separately and sought consensus with each other, the other co-authors, and the research literature about what meaning should be ascribed to the seven institutional logics from the theory proposed by Thornton, Ocasio and Lounsbury (2012) in the primary health care context.

#### *4.1.5 Theoretical perspectives*

Using multiple concepts that overlap but also differ (i.e., integrated care, goal-oriented care, person-centered care, patient participation and goal setting, and interpersonal integration), is a threat to specificity regarding the phenomenon one is studying as well as to transferability. However, to increase the credibility (internal validity) of each study, multiple concepts are included. Different concepts were useful to analyze empirical data from several perspectives (policy and service delivery at macro- and meso-level as well as patients and health professionals at micro-level). Patton (2015, 676) points out that



different kinds of data can yield somewhat different results, as they capture different nuances. Moreover, the design was emergent and not limited to a few concepts.

The institutional logics perspective (Thornton, Ocasio and Lounsbury 2012) illuminated how and why the actors justified patient participation differently. However, this perspective is not a means of assessing the quality of service delivery. The results must be interpreted accordingly. Moreover, the perspective is not well developed in the health services field, and the literature rarely discusses the question of which logics ideally *should* appear in that context. Beedholm and Fredriksen (2019) suggest that a theoretical model for studying patient involvement in the health care system should be expanded with a “patient logic.”

#### *4.1.6 Conclusion of the methodological discussion*

Researcher reflexivity was addressed at the end of the methods chapter (p. 58) to allow readers to assess the confirmability of the research process. I also aimed to provide sufficient information about the context, participants, and research process, and to offer quotations, to allow the reader to replicate the studies and assess the degree of similarity between the case studied and other contexts to which findings might be transferred (Patton 2015, 685; Graneheim and Lundman 2004).

The main methodological limitations are that the thesis is carried out in an early phase of implementation of the WMTY intervention and that the purposive sampling means that the results are not transferable to all older patients with multimorbidity or beyond the context of care pathways or rehabilitation in primary health care. The strengths are that different sources of data and methods were combined. This thesis provides transferable perspectives on goal-oriented, integrated care.

## *4.2 Discussion of results*

This thesis provides new knowledge about how patient participation emerged when the WMTY intervention was carried out. The results regarding normative integration indicated

that justifications for patient participation were partly shared, but the institutional logics supported a principle of individualization at macro-level and a principle of standardization at micro-level (Paper 1). The results regarding interpersonal integration indicated that health professionals attempted to share responsibility for service delivery with patients by taking four approaches to goal setting (Paper 2). Some patients experienced uncertainty about the course of disease and how to plan care. Three “games,” or patterns of interactions, occurred with varying levels of patient participation (Paper 3). In the processes adopted to achieve goal-oriented, integrated care, the meanings and levels of patient participation varied. Knowledge about goal-oriented, integrated care is important for future service delivery. Interpersonal and normative integration will be discussed in turn, followed by conclusions and implications.

#### 4.2.1 Goal-oriented, integrated care and interpersonal integration

Interpersonal integration is service delivery as a coherent social process, characterized by patient participation and shared goals (Singer et al. 2020). Collaborative interactions between health professionals and older patients with multimorbidity, which involve high levels of patient participation, are seldom reported in empirical studies (Pel-Littel et al. 2021; Couët et al. 2015; OECD 2019a). This thesis found that the level of patient participation was sometimes high (Papers 2 and 3). Those interactions aligned with the concepts of interpersonal integration (Singer et al. 2020) and collaborative goal setting to agree on a health-related goal (Vermunt et al. 2017). Agreement on goals is difficult when patients with multimorbidity have medical issues that are clinically dominant and time-consuming to handle and when resources in health services are insufficient (Rose, Rosewilliam and Soudy 2017; Lenzen et al. 2016; Levack et al. 2011). One explanation for agreement on goals in some care-planning meetings could be that the patients’ disease complexity was low, and that patients’ goals were in line with what the municipal health services usually afforded (Papers 2 and 3). However, for this patient group, participation may look different from descriptions in the literature of “shared decision-making” within

goal-setting interventions, where the parties, through dialogue and evaluation of options, agree on goals (Rose, Rosewilliam and Soundy 2017). Goal setting may require other interactions, such as when health professionals “vicariously” set goals, and this can represent interpersonal integration (Paper 2). The sample size of this thesis is not sufficient to determine how often collaborative interactions occur; this issue could be addressed in future studies.

#### *Medical complexity*

However, the actors’ attention to the medical complexity of multimorbidity can be prominent when the intervention is carried out. Health professionals often are “accused” of maintaining a medical focus, when a shift to goal-oriented care is required (Steele Gray et al. 2020; Reuben and Tinetti 2012). In the present thesis, health professionals, patients, and relatives used most of the time allocated for care planning to map and discuss the patients’ symptoms and the level of physical function needed to go home (Paper 1). As I and other authors have discussed, the dominance of the medical professional logic may circumscribe patient participation in the sense that areas for goal setting are predefined (Paper 1; Olsen et al. 2021). On the other hand, a strong medical focus may be necessary because patients’ conditions are complex. The goal-oriented, integrated care literature does not discuss possible consequences of patients *not* focusing on each of their symptoms. It is advocated that guidelines for single diseases should be set aside, based on the argument that multiple symptoms are too complex to handle simultaneously and that, through goal setting, fewer areas can be prioritized (Mold, Blake and Becker 1991; Muth et al. 2014). However, patients’ disease symptoms, impairments, or functional decline can be barriers to achieving what matters to them within other domains or to the possibility of them returning to their everyday life (Liddy, Blazkho and Mill 2014; Coventry et al. 2015). Thus, managing health and symptoms can be a way to achieve life goals (Tinetti et al. 2021).

Patients could also take a more passive role than health professionals because patients in an acute phase of disease or with four or more diseases have less desire to participate (Thompson 2007; Chi et al. 2017). In Norwegian health and care services, over 90% of older patients have multimorbidity, on average 4–5 diseases (Grimsmo 2018). Consultations with this patient group can be time-consuming due to medical and social complexity (Ekdahl et al. 2012). Thus, the WMTY intervention may primarily involve discussions of medical problems if it is carried out in care-planning meetings.

Patients' experiences of uncertainty influenced the process of collaboration in care planning. Some older patients experienced uncertainty about the further course of disease or perceived unpredictability in the care pathway (Papers 2 and 3). Uncertainty in decision-making is most often associated with physicians' consultations with patients in advanced diseases such as cancer (Etkind et al. 2017; Politi and Street 2011). This thesis suggests that uncertainty may occur for older patients without advanced disease who are in a care pathway on their way home (Paper 3). Patients' future is uncertain because the course of their diseases in combination with old age is unpredictable (Murray et al. 2005; Paper 3). Uncertainty may also be reinforced by the fact that the care pathway context requires decisions to be made rapidly. Norwegian patients aged 80 and over, stay an average of 15 days in short-term or rehabilitation wards (Norwegian Directorate of Health 2016). Care planning takes place early in patients' stays in the wards (Paper 3). One Norwegian study in a similar context found that health professionals perceived asking WMTY three days after older patients' hospital discharge was too early in the patients' recovery process (Nilsen, Söderhamn and Dale 2019). This presents a challenge because patients are expected to take an active role and be engaged in care planning in goal-oriented, integrated care (Steele Gray et al. 2020; Amelung et al. 2017).

This challenge is important to be aware of in future service delivery. The increasing number of individuals with multimorbidity has led to earlier discharge from hospitals (Damery, Flanagan and Combes 2016). In shorter care pathways, the patient role may

change. Patients who previously were in hospitals—that is, in an acute care context—can be asked for their contributions to service delivery before they have passed out of the acute phase of disease and reached a state of readiness to participate. For health professionals to enable patients to participate in the care process, they need to take individual capabilities and perceptions of illness into consideration (Leijten et al. 2018; Vahdat et al. 2014). A review found that patients' experiences of safety and security were associated with a trusting relationship with health professionals (Peart et al. 2020). This thesis suggests that health professionals can foster such a relationship by being aware of uncertainty, and they can initiate dialogue and adjust care planning to the temporal focus individual patients are able to adopt regarding the care pathway (Paper 3).

#### *Divergent goal-orientations in decision-making*

Few studies exist of the WMTY intervention within a Norwegian integrated care pathway for patients with multimorbidity. Service delivery based on WMTY has been hampered by fragmentation and profession-centeredness but is depicted as a promising approach (Berntsen et al. 2018). Some studies have found that health professionals' practices were oriented towards setting functional goals with patients (Olsen et al. 2020; Czypionka et al. 2020). One study within intermediate care units using a WMTY tool did also find service delivery to be standardized (Kvæl et al. 2019). Institutional logics representing professionals and cost efficiency dominated (Olsen et al. 2021; Kvæl et al. 2019).

Sometimes interpersonal integration was hampered by divergent goal-orientations and views of older age (Paper 2). Health professionals and patients can frame the situation and define appropriate goals for service delivery differently (Rose, Rosewilliam and Soundy 2017; Berntsen et al. 2015). In the results of this thesis, this meant that health professionals, patients, and relatives assessed the patients' state of health, rehabilitation potential in old age, and appropriate service delivery differently (Papers 2 and 3).

Divergent goals among actors are contrary to goal-oriented care (Steele Gray et al. 2020; Reuben and Tinetti 2012). Often, the interests of patients and families are neglected in

efforts toward integration (Singer et al. 2020). Older patients can feel that service delivery is pre-defined (Casado, Sousa and Touza 2020). Do health professionals and patients share decisions? The WMTY intervention was standardized in the sense that patients could participate within the confines of usual care within this care pathway, with the goal being for patients to recover and go home (Paper 1). The Norwegian guideline for WMTY recommends supporting patients towards independence and self-management (Norwegian Directorate of Health 2018a). However, some patients seemed reluctant to set goals, either due to uncertainty about their ability to improve their health or acceptance of age-related health deterioration as a natural part of life (Papers 2 and 3). The literature seldom discusses the question of what one realistically can expect from rehabilitation in older patients (American Geriatrics Society 2016; Looman, Huijsman and Fabricotti 2019).

#### *Objectives of goal-oriented care interventions*

Interpersonal integration and these conflicting goal-orientations of health services and patients may also be influenced by principles from health policies regarding integrated care. Health policies and the health system transfer the responsibility to maintain or increase health to older patients. The process of health professionals sharing responsibility with patients to make them co-producers instead of receivers of services (Paper 2) is comparable to ideas of patient independence in the WHO's guidelines on Integrated Care for Older People (ICOPE). Here, in the concept from 2016 of "healthy ageing," the goal is that older patients restore, cope, and maintain health. Health professionals help patients to develop and maintain their functional ability (WHO 2017). Similar objectives of patient independence appear in the policy regarding "aging in place" (Forsyth and Molinsky 2020). Moreover, integrated care includes the principle of co-production, in which patients and health professionals share decision-making and responsibility for service delivery (WHO 2016a, 4). The passages on co-production in the Norwegian welfare policy depict older people as able to control their services and plan to

live independently (Norwegian Ministry of Health and Care Services 2011; 2013). A principle of utilizing individual resources, duty, and responsibility for preventing health problems and relieving demand on services has entered the stage (Askheim et al. 2017; Amorim Lopes and Alves 2020). Obviously, actions in the municipalities are not necessarily directly influenced by a policy document, but they can be impacted by other streams in society as well, such as a general tendency towards individualization (Sørvoll and Gautun 2020). However, the process of sharing responsibility (Paper 2) can be understood in the light of the policies mentioned above. It can cause dilemmas about patient autonomy in goal-oriented care interventions, because in co-production patients can be voluntarily or involuntarily involved (Osbourne, Radnor and Strokosch 2016).

Do goal-oriented interventions reflect the different kinds of needs older patients with multimorbidity can have? Older patients are not usually stratified based on their health status in integrated care interventions (Khan, Hewson and Randhawa 2020; Monaco et al. 2020). Patients differ in patterns of diseases and symptoms and in physical, cognitive, and socioeconomic characteristics (Monaco et al. 2020). Different kinds of needs may have implications for the objective of goal setting. There are: goals for improving physical functioning and self-management but also; goals directed towards wellbeing and meaning in life (Håkonsson Eklund et al. 2019). Some patients have less reversible age-related conditions (Murray et al. 2005); therefore; some patients may need to prioritize to relieve a few out of multiple disease symptoms, while; others may be closer to advanced care planning (Gonzalez et al. 2019), which sets goals for care based on life values and wellbeing towards the end of life. In this thesis, the actors sometimes disagreed about which of these groups the patient belonged to. In rehabilitation interventions, assessment before application to individual patients is recommended: Firstly, which individuals would benefit and to what extent? Secondly, is the intervention wanted? These questions consider the complexity of aging, rehabilitation, and recovery (Cowley et al. 2021). Patients included in goal-oriented interventions could also have been stratified in a similar

way, based not on only the kind of ward they were in but also on their individual definition of health-related goals in older age. A dialogue before goal setting could reduce divergent goal-orientations and enhance interpersonal integration.

However, the results regarding how responsibility is transferred to patients can also be interpreted as enhancing person-centered care and patient participation. One dimension of these concepts is “sharing responsibility and power with patients” (Ebrahimi et al. 2021; Halabi et al. 2020). Older patients’ positive relationship with health professionals can enable negotiation to address individual preferences (Casado, Sousa and Touza 2020). Health professionals’ four approaches to sharing responsibility with patients can be understood as tailoring care to different patient situations and conditions. The identification of these four goal-setting approaches extends the literature on goal setting with older patients (Paper 2). This model can be used by health professionals in reflections about goal-setting practices.

#### 4.2.2 Goal-oriented, integrated care and normative integration

Normative integration links the macro-, meso-, and micro-level of health services through development and maintenance of a common frame of reference and goals for health service delivery (Valentijn et al. 2013; Steele Gray et al. 2020). The perspective of institutional logics made explicit a distance between the policy of individualized service delivery and, apparently, a principle of standardization of practices operating at micro-level (Paper 1). How can we understand that the normative justifications for patient participation were only partly shared between the macro-, meso-, and micro-level of health services? There are several perspectives that might help to understand this.

The meso-level is crucial for coordinating and aligning work with the macro- and micro-levels (Looman et al. 2021). Institutions are those who transform general policy intent into rules, routines, and social processes that can convert policy intention into action (O’Toole 2012). A study of integrated care across 17 countries including Norway found that the



meso-level of the organizations initiated most of this alignment compared to other levels. Political support from the municipalities enabled implementation, and the municipalities were an important stakeholder to increase commitment to the integrated care program (Looman et al. 2021). Strong leadership is frequently mentioned as important to this process (Calciolari et al. 2021). This thesis also found documents to be central in translating policy into practices, especially the tools for clinical practice, such as care pathway checklists. This process was influenced by institutional logics, and documents can possibly influence which logics transcend the levels of health services (Paper 1). In line with other studies, the meso-level was the “translator” of national policy into practice. Few studies exist of the linkage between levels (Briggs et al. 2018). Through the lens of normative integration, development of these documents can be seen as a social practice that can be subject to multiple interpretations of patient participation. However, the role of documents to the outcome for patients is unclear. One Norwegian study of this care pathway rather found that health professionals exercise discretion in how they use checklists (Nilsen, Söderhamn and Dale 2019).

The policy goals in the health reform describing WMTY are negotiated downwards through the levels of health services. A reform is a process of change that reform advocates see as improvements (Cain 2001; Marušič and Prevolnik Rupel 2016). However, the public administration literature points out that policy goals often are ambiguous and conflictual (Marušič and Prevolnik Rupel 2016; Matland 1995). Organizations may see the policy as relevant to its interests, but the means to carry out the agreed-upon policy differ. Goals can be unclear, or the means to achieve those goals may not exist (Matland 1995). This could provide a perspective on why normative integration of the intervention between levels seemed to be low (Paper 1). The Norwegian policy goals about WMTY are based on the principle of individualization (comprehensive services aligned with individual patients’ needs and preferences) (Norwegian Ministry of Health and Care Services 2018).

This may conflict with standardization of care pathways, as well as expecting patient independence and responsibility (Paper 1). This ambiguity of policy goals also applies to the “Triple Aim” of integrated care: to save costs while increasing quality and patients’ care experiences (Berwick, Nolan and Whittington 2008). Competing goals for health services may make it challenging to reach a single meaning of “patient participation” that transcends the levels of health services. What qualifies as successful implementation depends on whether the policy designer's values should be accorded a normative value greater than those of local actors (Matland 1995).

Integrated care does not involve a single ideology that is shared by all who promote it (Raus, Mortier and Eeckloo 2020). One review found that integrated care programs aimed to change *how* care was provided, improving the patients’ experience of care, rather than necessarily changing *what* care was provided (Hughes, Shaw and Greenhalgh 2020). The proposed shift of paradigm from patient disease- to goal-orientation (Reuben and Tinetti 2012) could also be viewed more as a change in the philosophy of care than a change at the practical level. In person-centered care, the attitudes of health professionals, such as “seeing the whole person,” and their communication skills are often highlighted as changing service delivery (Ebrahimi et al. 2021). However, goal-oriented care is a “sharper definition” of person-centered care because patients formulate their goals for health service delivery (Steele Gray et al. 2020). This is more about what services are delivered than about the interaction styles of health professionals. In this thesis, the emphasis on patient choice in goal formulation appeared mostly at macro-level (Papers 1–3). An unclear ideology about what to achieve may influence the extent of integration between levels of health services. To achieve normative integration, a common frame of reference needs to be developed among actors (Valentijn et al. 2013, 8).

Normative and interpersonal integration cannot be isolated from process, functional, and structural dimensions of integration (Singer et al. 2020; Looman et al. 2021). The view of whether the WMTY intervention achieves its aims could differ from the one in this thesis if

those dimensions were investigated. The Norwegian health services have a formal guideline, a health policy specifically about the WMTY intervention, regional learning networks, intervention tools, and the possibility of adjusting the intervention to local contexts (Norwegian Directorate of Health 2018a; Norwegian Ministry of Health and Care Services 2018). These elements are prerequisites for the social dimensions of integration, normative and interpersonal (Singer et al. 2020; Threapleton et al. 2017). In Norway, the implementation period of the health reform promoting WMTY extends until 2023 (Norwegian Ministry of Health and Care Services 2018). More studies are needed.

#### 4.2.3 Goal-oriented, integrated care: a paradigm shift?

What if goal-oriented, integrated care were not applied in health services? Across countries, improvements towards integrated care for older patients with multimorbidity started 5–10 years ago (Palmer et al. 2018; Rijken et al. 2016; Struckmann et al. 2018). Goal-oriented, integrated care for patients with multimorbidity is a new practice and research area. Change in health services often takes time (Lau et al 2015; Threapleton et al. 2017). Incremental growth, building upon what is already there, rather than a disruptive approach to innovation, can be important for adoption of interventions (Looman et al. 2021).

However, there is little evidence on outcomes to support the use of goal-oriented, person-centered care (Levack et al. 2016; Butterworth et al. 2020; de Bruin et al. 2020; Looman, Huijsman and Fabricotti 2019). Hughes, Shaw and Greenhalgh (2020) point out that few dispute the principle of integration and ask, “Who would want care that is *not* integrated?”. An aspect not addressed in this thesis is that goal-oriented care is implemented without accompanying financial resources for service delivery. This patient group has high utilization of services, and it is unknown whether goal-oriented, integrated care reduces costs, or is sustainable. A few critical reflections have arisen about the tension in health services between how to ensure standardization and individualization simultaneously (Kaehne 2018), and if person-centered interventions represent a

reductionist paradigm, which are standardized, narrowly focused interventions for complex problems (Berntsen et al. 2019).

The complexity of service delivery for older patients with multimorbidity, as highlighted in this thesis, is that the actors can face challenges to set appropriate goals due to the complexity of patients' diseases in combination with functional decline in older age; uncertainty that hampers the planning of care pathways as a streamlined process (Paper 3); and diverse goal-orientations among actors that are influenced by the context within which they act. Can increasing patient participation through goal-setting interventions reduce these complexities, and generate a paradigm shift in health services?

## 5. Conclusions

### 5.1 Conclusion

The thesis investigated goal-oriented, integrated care for older patients with multimorbidity in Norwegian primary health care. This thesis supports the argument that integrated care can be understood as a set of emergent social practices among multiple actors that do not produce a predetermined set of outcomes, such as patient participation. When care planning within the "What matters to you?" intervention is carried out, the justifications for and levels of patient participation can vary. In terms of normative integration, the justifications for patient participation within the WMTY intervention in principle were individualization at macro-level and standardization at micro-level.

Interpersonal integration was explored in how patients participated in the WMTY intervention. Health professionals took one of four approaches to set goals and share responsibility with individual patients. The complexity of multiple diseases in combination with older age and a patient perception of uncertainty about the care pathway can be associated with lower levels of patient participation. Moreover, the organizational and political context expecting an active patient role may not always be supportive for

achieving goal-oriented care for some older patients. However, the level of patient participation sometimes was high. This thesis provides new knowledge about what the social side of integration looks like in goal-oriented, integrated care.

## 5.2 Implications for practice

This thesis has several implications for the different levels of health services to facilitate goal-oriented, integrated care.

- It raises the question of whether the Norwegian health reform's goals for individualization through WMTY, and its application in municipal strategy plans, were too comprehensive to be carried out. The reform allows patients to set goals within multiple domains, to choose what services to receive, when, and from whom (Norwegian Ministry of Health and Care Services 2018). Individualization also appears in the policy of integrated care by the WHO, which is to be implemented in the member countries (WHO 2016a). As the number of older people increases, the capacity of the health services to carry out intended reforms aimed at individualized service delivery may be limited. Future health reforms could consider, based on empirical studies, the extent to which individualized service delivery can take place in primary health care. Actors in local context may also need to discuss how they can operationalize patient participation.
- The meso-level can be aware that institutional logics in health services can influence how the tools for clinical practice are designed. This thesis found that the tools consisted of little text, which could allow for multiple interpretations at micro-level (Paper 1). The theory of institutional logics points out that the actors' beliefs, values, and different goals influence action (Thornton, Ocasio and Lounsbury 2012). Considering this, the tools could include justifications for why and how patients should participate.
- Goal-setting tools and materials, such as care pathway checklists, need to include several domains of goals to broaden the scope of the goals of patients.

- In care planning with older patients, health professionals can possibly increase patient participation by being aware of potential uncertainty among patients (and relatives) about the course of disease and how they can participate in service delivery.
- To reduce some patients' perceptions of uncertainty, health professionals can inform them about the process of allocation of services and the usual course of the diseases they have. Patients may also need to discuss uncertainty and perceived risks about the decisions that are made. Moreover, health professionals could elicit patients' temporal focus and adjust the timeframe of goals accordingly.
- The concept of health professionals' four approaches illustrates how goal setting can be carried out with different patients (Paper 2).
- To enhance a goal-oriented approach in medically complex situations, one suggestion is to divide care planning into one meeting for discussing symptoms and treatment and another one for discussing what matters to patients in other domains, such as social and everyday life and life values. This could benefit patients, as medical complexity takes time to discuss, and patients often experience fatigue.

### 5.3 Suggestions for further research

Based on this thesis, further research about goal-oriented care could investigate the following topics.

- This thesis found varying levels of patient participation. The levels of patient participation within WMTY, or other goal-oriented interventions, could be measured within a large sample. It is important to evaluate to what extent older patients with multimorbidity participate.
- The level of patient participation was high in some situations—why? Future studies could identify which decision-types and conditions of patients this result is associated with in this context.

- Based on the findings of uncertainty in care pathways for older patients with multimorbidity, future research could examine whether and how perceptions of uncertainty influence what kind of goals are set, who sets the goals, and goal attainment over time. How often do goals in care planning become unachievable due to unpredictable factors? Do patients who experience uncertainty (dis)agree with their care plan? What is the prevalence of perceptions of uncertainty?
- Case studies that investigate which institutional logics appear within goal-oriented, integrated care in other contexts could provide new knowledge about how patients are entitled to participate and what meaning goal-oriented care has. For example, some health systems may be regulated more by a market logic, while the logic of family or religion can play a greater role in other contexts.

A need for further research was identified in the literature review for this thesis, which revealed that literature reviews about goal-oriented, integrated care are few. What meanings does goal-oriented care have? The answer to this question differs slightly across occupations and contexts. A review could group and compare the theoretical underpinnings of goal-oriented care and the actions involved. This could be helpful for designing goal-setting tools, writing guidelines, and stratifying patients into different goal-oriented intervention types. More conceptual clarity may also be needed to enhance integration.

Given the growing number of patients with multimorbidity, further research must continue to investigate how older patients with multimorbidity can participate in the future health system.

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Papers 1–3





# Paper I



RESEARCH ARTICLE

Open Access

# ‘What matters to you?’ Normative integration of an intervention to promote participation of older patients with multi-morbidity – a qualitative case study



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## Abstract

**Background:** Interventions in which individual older patients with multi-morbidity participate in formulating goals for their own care are being implemented in several countries. Successful service delivery requires normative integration by which values and goals for the intervention are shared between actors at macro-, meso- and micro-levels of health services. However, health services are influenced by multiple and different institutional logics, which are belief systems guiding actors' cognitions and practices. This paper examines how distinct institutional logics materialize in justifications for patient participation within an intervention for patients with multi-morbidity, focusing on how variations in the institutional logics that prevail at different levels of health services affect vertical normative integration.

**Methods:** This qualitative case study of normative integration spans three levels of Norwegian health services. The macro-level includes a white paper and a guideline which initiated the intervention. The meso-level includes strategy plans and intervention tools developed locally in four municipalities. Finally, the micro-level includes four focus group discussions among 24 health professionals and direct observations of ten care-planning meetings between health professionals and patients. The content analysis draws on seven institutional logics: professional, market, family, community, religious, state and corporate.

**Results:** The particular institutional logics that justified patient participation varied between healthcare levels. Within the macro-level documents, seven logics justified patients' freedom of choice and individualization of service delivery. At meso-level, the operationalization of the intervention into tools for clinical practice was dominated by a state logic valuing equal services for all patients and a medical professional logic in which patient participation meant deciding how to maintain patients' physical abilities. At micro-level, these two logics were mixed with a corporate logic prioritizing cost-efficient service delivery.

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**Conclusion:** Normative integration is challenging to achieve. The number of institutional logics in play was reduced downwards through the three levels, and the goals behind the intervention shifted from individualization to standardization. The study broadens our understanding of the dynamic between institutional logics and of how multiple sets of norms co-exist and guide action. Knowledge of mechanisms by which normative justifications are put into practice is important to achieve normative integration of patient participation interventions.

**Keywords:** Health care reform, Practice guideline, Patient participation, Patient care planning, Institutional logics, Normative integration, Delivery of health care, integrated, Vertical integration, Multimorbidity

## Background

Facing aging populations, Western countries and their health authorities are looking for new ways to deliver health services according to patients' needs. New practices go under various names, such as 'integrated care,' 'integrated service delivery,' or 'joint working' [1]. 'Integration' means combining organizational parts into a unified, synergistic whole [2]. Actors within the health system may have different views, interests and objectives [3]. The goal for patient care is not always shared, either across care settings or between health professionals and patients [4–6]. More than 60% of people over 65 have multi-morbidity, meaning they have two or more chronic diseases [4]. Patients with multi-morbidity often have complex health needs and functional decline and are dependent on long-term health care from several services [7]. In the past, individual older patients have been minimally involved in decisions about their care [8, 9]. A paradigm shift within the health system – towards letting patients' values, needs and preferences direct health service delivery – is now required. Goal-oriented care is designed to engage patients in setting personal goals and to align care to attain these goals. This practice is assumed to increase patients' health and self-management, improve quality of care and reduce costs [5, 6, 10–12]. Goal-oriented care is being included as an intervention within integrated care models and in clinical guidelines [4, 6, 13, 14]. However, in practice, integrated care proves difficult to accomplish [15–17].

Evidence indicates that normative integration ensures collaborative processes within the health system [2, 18]. Normative integration means that actors have a common frame of reference and shared values and goals for service delivery [16, 19]. Values and goals must span the micro- (professional), meso- (municipal/organizational) and macro- (national/government) levels of health services. Vertical integration through these levels is a condition for implementation and accomplishment of integrated service delivery [13, 20, 21]. So far, research shows that normative integration of interventions is negligible, and research into how normative integration functions is itself sparse [19–21]. Normative drivers may facilitate or constrain patient participation, and empirical

studies of how values connect to behavior are called for [13, 15, 21]. To reduce this knowledge gap, the present paper investigates normative integration from a novel perspective, connecting values with actions by focusing on how actors at different healthcare levels are guided by particular institutional logics. Institutional logics are societal belief systems which provide actors with frames of reference that precondition their sensemaking choices [22]. The lens of institutional logics is here applied to an initiative meant to enable goal-oriented care in Norwegian municipal health services.

### The institutional logics perspective

This perspective understands individual and organizational behavior within the societal and institutional context [23]. The viewpoint developed out of a critique of the ways in which institutional analysis ignored issues of change and the effects of human agency [24]. Institutional logics considers 'the socially constructed, historical patterns of cultural symbols and material practices, assumptions, values and beliefs by which individuals produce and reproduce their material subsistence, organize time and space, and provide meaning to their daily activity' [25] p.51.

Studies have typically examined institutional logics by using typologies, and one of the most influential typology is presented by Thornton, Ocasio and Lounsbury [22, 23, 25]. According to these authors, institutional logics are embedded in seven societal institutional orders which, to varying extents, govern actors and fields: the family, the community, religion, the state, the market, the profession and the corporation [25]. These orders highlight the interplay between individuals, organizations and institutions from macro- to micro-level and vice versa [25]. The logics they embody establish core principles according to which actors organize activities and channel interests. Logics shape action [25], and actors in turn draw on different institutional logics for meaning and motive. Actors can manipulate and elaborate different logics for their own advantage and to change social relations [23].

Institutional logics have regulative, normative and cognitive dimensions. The normative dimension is

connected to actors' values and goals [25, 26] and can illuminate normative integration between healthcare levels involved in the patient participation intervention under consideration in this study. Values are conceptions of what is preferred or desirable, and values supply standards according to which existing structures or behavior can be assessed. Norms specify how things should be done; they define legitimate means of pursuing valued goals. Institutional logics constitute various justifications for why goals should be pursued in health services [26], see Table 1.

While the literature suggests that individuals and organizations are confronted with diverse normative requirements and multiple institutional logics, studies of health services have typically focused on two to three competing logics [25, 26]. The professional logic has traditionally dominated research on health services; however, some studies shift the emphasis toward corporate and market logics [33, 26]. Health professionals may experience incompatibility of values between the professional logic and corporate principles, as business-based models of health care in which governance structures have been changed to increase efficiency and 'do more with less' [34] and an emphasis on cost-effective treatment and using the lowest-cost provider compromise patient participation [35, 36]. The logics of religion and family are currently underexplored in relation to health services

**Table 1** How the basis of norms differs between the seven institutional logics

Logic	
The professional logic	..entails autonomous judgment based on specialist knowledge. Norms are professionally developed and controlled by others in the profession [25, 27].
The corporate logic	..allows actors to achieve organizational goals through reproduction and efficiency by gaining authority over others [28]. Routines and administrative control of managers determine norms and procedures [27, 29].
The market logic	..lets consumer preferences, satisfaction and choice determine norms within the context of a broader market [25, 27, 30].
The community logic	..means that group membership gives a sense of belonging, maintained through reciprocities, trust and commitment to shared values. This supplies local norms for organizational practices [25, 31].
The state logic	..involves securing social and political order [32]. The government takes direct responsibility for health care and determines appropriate quality standards for care [27]. The basis of norms is citizenship in a nation [25].
The family logic	..involves fellowship and unconditional loyalty to family members and their needs [24]. Norms are related to membership in household [25].
The religious logic	..emphasizes the importance of faith and sacredness. The basis of norms is membership in a congregation [25].

[37]. Few studies have examined multiple logics between levels of health services [38].

When multiple logics are in play, they may facilitate or constrain action [33, 27]. The constellation of institutional logics describes the relationship among multiple logics at a given time. If increase in the strength of one logic does not correspondingly decrease the strength of another, the constellation is cooperative. In a competitive constellation, increases in the strength of one or several logics correspond to a decrease in the strength of another. Nondominant logics carry less force in guiding behavior [25, 27]. Few studies have explored how multiple institutional logics influence health services for older patients with multi-morbidity. This relates to the call for research on normative integration, exploring whether actors share goals and whether cultural norms support formal protocols [2].

#### The case: vertical integration of an intervention involving patient goal setting

The Norwegian case is typical of a paradigm shift seen in a number of high-income countries over the past decade toward health policies designed to increase patient participation and health services which implement integrated care models [4, 13, 14, 39]. The case is a specific goal-setting intervention, examined through analysis of the health policy that triggered the intervention, a clinical guideline, intervention tools and health professionals' practices. We do not evaluate the implementation process; rather, we focus on the justifications offered for increasing patient participation and the institutional logics in play in those justifications in order to understand whether and how vertical normative integration occurs between health service levels.

The case is based on a health reform for Norwegian municipalities proposed in the white paper "A full life - all your life A Quality Reform for Older Persons" [40]. This white paper and an accompanying national guideline are key instruments for increasing patient participation [40, 41]. The target group of the reform is actors who deliver health services for people over 65 years who live at home or in institutions [40]. The guideline for follow-up with patients with multi-morbidity has a similar objective [41].

The Norwegian state is social democratic and universalist [42]. Services for older people are broadly accessible and are primarily financed, organized and delivered by public entities in the municipalities [43]. These entities include facilities for rehabilitation and long-term care, which takes place in community hospitals for rehabilitation, in nursing homes, or in patients' homes. Patients can also receive time-limited and intensive rehabilitation service in their homes.

The intervention entails that when individual patients are allocated health care services by their municipalities, health professionals ask each patient ‘What matters to you?’ to enable patient participation in decisions about how these services should be delivered [5, 41]. A goal for care is formulated and documented with the understanding that patients and health professionals will work together towards this goal. This planning of care with patients occurs either in conversations with one health professional or during interprofessional meetings. Health professionals include nurses, auxiliary nurses, physicians, physiotherapists and occupational therapists. Patients’ goals may relate to reducing symptoms or improving physical functioning or well-being; goals can also have social dimensions or be related to life values [6, 41].

Integrated service delivery often takes place in collaborative networks spanning levels [21]. This is a form of collaboration based on social commitment rather than a formal hierarchy of the kind that might be seen under traditional top-down governance, based upon legal duties or market-based contracts [44]. Within newer forms of governance, guidelines are issued from the macro-level, but each level determines how to carry out its responsibilities. The white paper and the guideline offer normative recommendations, which may be adjusted to local contexts by each municipality [40, 41]. Actors across levels in Norwegian municipalities can participate in a national collaborative quality improvement network for integrated care, in which the intervention is proposed [45]. The intervention is operationalized at the meso-level through the development of tools which are then used by health professionals carrying out the intervention at the micro-level. A dynamic interaction ideally occurs between the policy level and micro-level norms and behaviors [2]. Actors need a shared vision of why interventions should be carried out [17]. However, little is known about how institutional logics influence actors’ justifications for encouraging patient participation. To illuminate vertical normative integration within Norwegian municipal health services for older patients with multi-morbidity, we ask:

- 1) In what way are normative justifications for patient participation connected to different institutional logics?
- 2) How do the constellations of institutional logics vary between the macro-, meso-, and micro-levels of health services?

## Methods

### Design

A qualitative case study method allows the examination of the intervention and the institutional logics at work. This study includes three embedded units of analysis

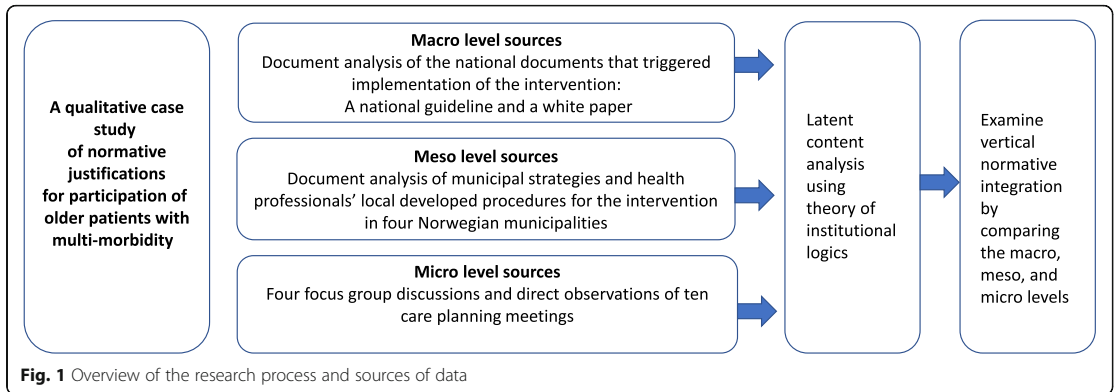
(macro-, meso- and micro- levels) [25, 46]. The institutional logics perspective is grounded in social constructivism, in which beliefs and norms held by institutional actors are seen as socially constructed and shared [25]. The case study allowed us to observe these shared norms within the actors’ context and to triangulate data to achieve ‘thick’ descriptions [46–48]. Institutional logics are captured in language, practices and materials [49]. Thus, to achieve our aims, we combine analysis of the documents that triggered implementation of the intervention, focus group discussions and direct observations of meetings between patients and health professionals [46, 48, 50]. Figure 1 gives an overview of the research process. All sources of data were analyzed using latent content analysis, which seeks the underlying meaning of the text [51]. We associate this underlying meaning with relevant institutional logics [25]. In line with constructivist approaches, descriptions produced in this study and results obtained are considered to be interpretations influenced by the researchers and their context [48].

### Sample

To investigate normative integration, we selected data which contained normative statements about patient participation and covered different actors’ perspectives. We purposively chose four municipalities which had implemented the intervention and carried it out as described in the introduction to this article. These municipalities participated in a national collaborative quality improvement network for integrated care [45] and implemented the intervention 6–12 months prior to our data collection. The municipalities are located in Western Norway. Two are rural, with 2000–3000 inhabitants each, while two are cities with 40,000 and 70,000 inhabitants.

### Documents

Sampling of documents was purposive: We selected all macro-level documents designed to be used by all levels of the health system which contained guidance and normative recommendations for carrying out the intervention. The governmental white paper ‘A full life - all your life A Quality Reform for Older Persons’ describes how ‘What matters to you?’ should form the basis of service delivery [40]. Institutional logics tend to materialize in white papers, which are, among other things, attempts to govern meanings about what should be done, and which exemplify the dominant official narratives of their times [52]. The clinical guideline for follow-up of persons with complex needs is the first Norwegian guideline describing integrated care for older patients with multi-morbidity [41].



At meso-level, municipal strategies for eliciting the participation of individual patients were extracted from the municipalities' web pages. We used search terms that covered care pathways for older patients with chronic diseases, patient participation at the individual level and the phrase 'What matters to you?'. We included all text concerning these matters, which was amounted to 500–1000 words per municipality. To protect the anonymity of study participants, we do not refer to these webpages, as doing so would identify the particular municipalities. The municipal strategies were included to examine whether the intervention was included in prevailing policy within each municipality. To capture the institutional logics being applied in local materials [25], we also considered tools used by health professionals to enable the intervention, such as care pathway checklists.

#### Focus groups

To examine health professionals' justifications for patient participation, we arranged one focus group discussion [50] in each municipality, convening health professionals from multiple sites. One participant with no health education was included because health education is not required for all employees in Norwegian municipal health services. Managers or municipal workers issued invitations, either in person or by email, to 27 health professionals who worked in clinical settings and had experience with the intervention.

#### Observations

Ten care-planning meetings in which the intervention was carried out were observed. Eligible patients had two or more chronic diseases and a current need for more health services. The intervention was a component of municipalities' integrated care pathways for older patients with multi-morbidity. The pathway was mainly used for patients over 80 but could be used for younger

patients in rehabilitation wards. We aimed for a purposive sample of meetings, representing different kinds of wards and different stages of the care pathway. Health professionals recruited patients, and the meetings we observed were planned independently of this study. Patients in the end of life-phase or with cognitive impairment were excluded.

#### Data collection

##### Documents

In August 2019, we retrieved the national guideline [41], the white paper [40] and the municipal strategies for health services from the internet. We thoroughly read the white paper "A full life - all your life A Quality Reform for Older Persons" [40]. Then, we extracted the chapters describing patient participation: Chapter 1 ('Goals and target group'), Chapter 7 ('Health care') and Chapter 8 ('Coherence'). From the guideline [41], approximately 20 of 63 pages were excluded because they referred to younger patients or other organizational work tasks. The meso-level care pathway checklists and tools developed for health professionals who carried out the intervention were identified by, and collected from, health professionals in each municipality from October 2018 to December 2019.

##### Focus groups

The focus group discussions [50] occurred from September 2018 to February 2019. Each of the four groups consisted of 5–7 participants. They took place without interruption in meeting rooms at participants' workplaces. A semi-structured interview guide prompted health professionals to describe and discuss goal-setting situations they had experienced in care planning with older patients with multi-morbidity. The interview guide was developed by the first author to elicit information about health professionals' patient participation practices, that is, what they had done in specific situations.

We asked for their justifications for why and when they could (or could not) act upon patients' preferences. This allowed us to examine the salient institutional logics governing their justifications, even though we did not explicitly ask about institutional logics (see Additional file 1 for the interview guide). The discussions lasted an average of 90 min.

### Observations

The first author conducted direct observations of care-planning meetings in which she attempted to assume a neutral role [48]. She engaged in small talk before and after meetings but did not speak during the meetings. An observation guide developed by the first author was filled out about the setting and patient participation in goal setting (see Additional file 1). The health professionals were told that the aim was to observe the intervention; however, they were not told in detail which aspects were being observed. The observations were made from October 2018 to December 2019. Except for one meeting, all interviews and observations were audio-recorded and transcribed verbatim. The first author previously was a hospital nurse for older patients with multi-morbidity. The transcripts allowed the co-authors, who have different backgrounds, to interpret the material. Field notes were written immediately after each observation. The meeting agendas were similar across these settings; therefore, ten meetings were sufficient to assess how the intervention was carried out.

### Analysis

We started by analyzing the macro-, meso- and micro-levels separately. Subsequently, we looked at the whole of the case and compared the three levels [46]. All sources of data were analyzed using latent content analysis. The analysis process comprised four steps: decontextualization, recontextualization, categorization and compilation [51]. In the decontextualization phase, theory and definitions of the seven institutional logics (see Table 1 in the introduction) gave guidance for initial codes of all documents and transcripts [51]. To identify normative justifications for patient participation, we coded statements such as 'health professionals/the services should...' and 'the goal is to ...' and statements of why participation was important. JDO and RK separately coded the data and regularly discussed coding with each other and the co-authors. It was essential through the analysis to interpret the whole of all texts to understand the case. Texts which could be coded to two logics were discussed to reach consensus. During the recontextualization phase, meaning units and text extracts were inserted in tables. Text not relevant to the research aim was excluded. In the categorization phase, we found properties of the seven institutional logics and the

constellations they constituted at each level. The logics in the documents were classified as weak or strong depending on how frequently they appeared, how thoroughly they were described and the normative words (health professionals 'should' or 'have to' vs. 'can', e.g.) with which they were associated. At micro-level, the strength of logics was determined by how frequently they appeared and whether one logic seemed to prevail over another in guiding decision-making with patients [25]. Logics neither mentioned by participants nor found in materials were coded as 'did not appear'.

The ways in which the institutional logics were applied to patient participation were coded according to justifications for, and aspects to consider, when encouraging patients to participate [35]. Table 2 gives an example from the coding process.

In transcripts from micro-level, we examined how active patients were expected to be in goal setting: from being excluded, to being informed about decisions, to being invited to express their preferences or collaborate in goal setting [6, 8, 35].

In the compilation phase, we examined the constellation of logics across the macro-, meso- and micro-levels, interpreting the constellation of logics at each level as either facilitating or constraining patient participation. Finally, to assess normative integration, we compared the constellation of logics vertically across health care levels [2, 27, 53]. The software NVivo 12 Pro qualitative data analysis software (Melbourne, Australia: QSR International Pty Ltd., 2018) supported the analysis. The Norwegian text extracts were translated to English by a translator after the analysis.

## Results

### Participants

Three invitees to the focus groups did not attend due to illness. Participants included four head nurses in nursing homes, one head nurse in home care services, seven nurses, one caseworker, three auxiliary nurses, two occupational therapists, four physical therapists, one physician and one person without health education. Two of the focus groups has one male participant each. Five participants were between 20 and 30 years old, 10 were between 30 and 40, four were between 40 and 50 and five were 50–65 years old. In the observed care-planning meetings, the mean age of the ten patients was 88 (with a range from 62 to 98); two were men and eight were women. All patients had multi-morbidity. Plans were made for eight patients to go home and two to receive long-term care in institutions. Four of the meetings were carried out by a nurse, and these lasted an average of 32.5 min. Six meetings were carried out by an inter-professional team, and these lasted an average of 47 min. Relatives participated in seven of the meetings.



**Table 2** Example from coding of the state logic

Data	Units of meaning	Subcategories	Theme
<b>Extract from white paper:</b> "Older persons should feel valued, seen and be able to participate in decisions which involve them. They should have the opportunity to live at home as long as possible, and receive support to master their everyday lives, regardless of illness or functional impairment" [20] p.121.	Seen as individuals. Supported mastery, with focus on living everyday life. Treatment at home is the norm. Support from health system. Reduced health no obstacle.	The state determines quality standards for care and role of the health system [27]. The state expects older persons to participate in order to master life at home.	Individualized service delivery

This section proceeds by firstly explaining how normative justifications for patient participation were connected to different institutional logics at the macro-, meso- and micro- levels of health services. Secondly, it discusses how the constellations of institutional logics vary vertically through the levels of health services.

#### The macro-level documents: multiple cooperative logics

All seven institutional logics from the theoretically based typology [25] appeared in the white paper and guideline. The institutional logics were associated with distinct views of patients and particular justifications for increasing patient participation. These justifications aimed to allow patients to become drivers of their own lives. The guideline called for a paradigm shift towards more patient participation, arguing that health services should take a holistic approach by allowing multiple areas of individual patients' lives to be acknowledged in the formulation of plans for service delivery [41] p.15-16. A main point was to shift from a traditional professional mindset in which medical knowledge guides care planning.

The question [What matters to you?] also poses a challenge for the traditional professional role as an 'expert'. It's about aiding the person in finding optimal individual solutions rather than giving fast answers. (guideline, [41] p.16).

Both the guideline and the white paper described a mode of service delivery not dominated by health professionals' medical judgments. A shift towards patient empowerment, including the further development of professional skills such as listening and transferring power to patients, was emphasized. This gave the professional logic a more person-centered emphasis. The white paper invited actors in health services to think differently about older people, who were presented as members of a local community, having individual life stories and personal interests and activities to be included in care planning.

A person-centered approach involves (...) seeking to understand the world from the individual's perspective and accommodate his or her social and psychological needs. The residents' life stories, values and preferences should form the foundation for formulating and carrying out the services. (white paper, [40] p.149–150).

Moreover, care planning could support older people to master the tasks of everyday life and remain involved in their communities despite functional decline [41]. The white paper pointed out that people prefer service delivery at home. Both the guideline and the white paper stipulated that services should be delivered in a family and social-network perspective. These recommendations reflected perceptions of older persons as family members in their community, perceptions which indicate an interplay between the family and community logic. Hence, relatives with a caregiver burden should also be given greater opportunities to participate.

The services should make room for participation of the patient's loved ones, family, and network according to the patient's wish. (guideline, [41] p.16).

The documents emphasized that to achieve these goals, services should not be planned according to standardized routines of service delivery. Moreover, the white paper drew on principles from a market logic in descriptions of older patients as consumers with freedom of choice.

'Live Your Whole Life' is a reform intended to provide a greater freedom to choose. It should give each individual better opportunities to choose service providers (who), be involved in the content of the services provided (what), determine the manner in which services are provided (how), and the time and place for the provision of services (where and when). (white paper [40] p.10.

Giving patients freedom of choice would be beneficial in the context of the logics of both market and corporation: patient participation was justified by its benefits for patient health. Supporting patients to attain control of their own lives and maintain their health would subsequently lead care processes to become more efficient.

Several of the suggested solutions can increase the efficiency of the services and decrease the need for help for the elderly in the long term. (white paper [40] p.175.

Moreover, the white paper requested that health professionals address individual patients' faith, philosophical practices or need to discuss existential questions. However, few other statements associated with a religious logic were present, indicating that this logic was weak. Thus, the content of the white paper and guideline modified the professional logic and strengthened the logics of community, family, market and religion, which were all associated with individualized service delivery that would take social and psychosocial dimensions of patients' lives into account.

The logic of the state provided a broader societal justification for patient participation. Including older citizens as co-producers of service delivery would increase society's capacity to handle the growing population of older people. Older peoples' functional abilities often decline, so they were expected to take an active role by setting goals to maintain health.

For health and care services, this will mean, among other things, being more resource-oriented and placing greater emphasis on proactivity, early intervention, prevention and everyday coping, often based on the basic question: What is important to you? Most people want to participate and manage themselves for as long as possible, and that is also the best for the community and future sustainability. (white paper [40] p.53.

One goal of the intervention was to provide equal treatment and reduce geographical inequalities. Tools were suggested to improve quality-of-care pathways, such as the Patient-Specific Function Scale [54] and checklists. This suggests that the intervention was governed by the logic of the state. Equal treatment, however, introduced ambiguities in the context of the intervention to individualize services, because the guideline described standardization as a complex task due to the inherent complexity in patients' multiple diseases and their need to make use of several services within fragmented organizations.

In follow-up of patients (...) there are limits to how much it can be standardized. (guideline [41] p.7.

In sum, the white paper and the guideline reflected the intention of reducing competition between different logics, e.g. dominant professional logic and the hitherto weaker logic of family. The suggestions within the documents for increasing patient participation by including several areas of patients' lives can be associated with an effort to give equal value to multiple institutional logics, which is a move towards a cooperative constellation of logics. The constellation of logics at this level, in sum, constituted the following norm for patient participation: Health services enable patients to be the drivers of their own lives and live full, independent lives in their communities with support from health authorities. To achieve this, local solutions in the municipalities were called for.

#### **The meso-level documents: From a constellation of multiple cooperative logics to two dominant logics**

The move articulated at the macro-level towards a cooperative constellation of logics was manifested in municipal strategies for individual patient participation, as described on public municipal websites. The municipalities described 'What matters to you?' as an individualized basis for service delivery, often referring to the white paper. Methods to incorporate patient participation in health services were described in general terms rather than in terms of detailed practices.

There should be a focus on user participation, and everyone involved must ensure user participation when making decisions. (Strategy plan on website, Municipality 2, rural).

To guide health professionals' practice, each ward had written tools for goal setting with patients. These had been developed by health professionals, often ward managers, or adopted from other municipalities.

The tools used differed between municipalities (Table 3), but in general they had two main functions. The first function was to plan how patients could manage at home.

This procedure is aimed at follow-up of patients discharged from the hospital who need a plan going forward for what steps need to be taken for the sake of continuity in their care pathway. Meeting agenda: Map out and plan future care needs with returning home as the end goal. (Written agenda for interprofessional meetings with patients, Municipality 3, rural).

**Table 3** Intervention tools developed at meso level

Intervention tools	Municipalities			
	1	2	3	4
A 'What matters to you?' questionnaire based on the Patient-Specific Functioning Scale [54], used to set goals for physical rehabilitation.	x			x
Pocket cards for health professionals, with three questions to elicit patients' rehabilitation goals.	x			x
Form to fill in medical information about new patients, with 'What matters to you?' as one of approx. 15 items.	x	x		
Written agendas for care-planning meetings, in which elicitation of patients' goals for their care pathways was one component			x	x
One-to-two-page care pathway checklists with an open-ended question 'What matters to you?'	x	x	x	x

Secondly, the tools were used to obtain an overview of medical information and physical function.

*The meeting agenda: a plan for the road ahead.*

What was your condition before your last hospitalization? How are you now? How would you like your condition to be? What needs to happen for you to achieve that? (Written agenda for care-planning meeting. Municipality 4, city).

These tools had the effect of limiting the areas within which patients could set goals. From macro- to meso-level, the professional logic shifted from empowering patients to master what mattered to them to letting medical knowledge guide formulation of goals for service delivery. The professions followed medical standards by including "What matters to you?" as one of many items on existing forms used to map medical information about patients. Moreover, the fact that the question was integrated into care pathway checklists for patients with multi-morbidity could be interpreted as expressing a state logic emphasizing standardization and bureaucracy, in which as much focus is given to asking all patients as is given to their answers. The focus group discussions at micro-level reflected such ideas. Moreover, a weak corporate logic was also in play, because these checklists served the function of facilitating managers' control by process-evaluation of whether professionals at the ward had asked all patients the required questions. What is more, through these tools, patients' goals were pre-defined in terms of going home. In this way, the tools restricted which health services and areas of patients' lives services could focus on.

The texts at meso-level contained fewer logics than at the macro-level. We found few justifications for patient participation rooted in a logic of family. The tools had no text that prescribed that health professionals should solicit relatives' preferences in decision making or attend to the patient's position in a family. The logic of community was weak as well; the actors who developed the tools apparently less considered patients' positions or participation in a community, life stories, or interests and hobbies. The market logic which, at macro-level, emphasized individual choice did not appear here. The

tools in use did not encourage patients to choose times or places for service delivery, nor to determine which health professionals to involve or how the allocated services should be delivered. Attending to patients' religion was briefly mentioned in one of the municipalities' strategy plans and in one of the tools. Moreover, the tools indicated that a corporate logic dominated over a logic of family, since the help text for health professionals in the tools described family members as helpers in patients' management at home and, thus, contributors in service delivery.

Ask the patient: 'Do you have family or friends who assist you with your everyday chores or activities?' Ask what patients' relatives can do to help patients achieve their goals. (Tool for health professionals, pocket card. Municipality 4, city).

The cooperative constellation of multiple logics found at the macro-level broke down in the written tools in use at meso-level: several logics became weaker as the intervention was operationalized and adjusted to the health services' existing structures. The logics of profession and the state dominated in determining how questions to patients were formulated. The tools often had sparse guidance text informing health professionals of how, why, and with what consequences they should ask patients 'What matters to you?'. Overall, the constellation of logics in operation at the meso-level constituted the following norm for patient participation: All patients should participate in setting goals about how to manage to live at home.

**The micro-level practices: three dominating logics**

This level includes focus groups with health professionals and observations of care planning meetings. The emergent theme from the focus groups was that multiple logics in the field created a tension between individualized and standardized service delivery. Health professionals perceived their practices to have changed because of the intervention – they felt more aware of patients' preferences. Health professionals reflected the white paper's view of the professional logic, to empower patients to find individual solutions.

P2: I'm thinking that since we started asking "What is important to you?" it has maybe become easier to focus on their goals. Before, we might have been the ones saying: "Yeah, maybe it is important for you to use a walker," rather than "Can I use a walker?" But now it is more up to them to say that, before we come in, at least. And I think they see that as a positive thing.

P1: It has been a gradual shift, from a national health service with a very paternalistic approach where we know what is best for you. Now it's more like we are more...we are on their team. (P1: Head nurse P2: Occupational therapist, both at rehabilitation ward. Focus group in municipality 1, city).

There were, however, some discrepancies between the comments made in focus groups and what we observed in meetings regarding the extent to which health professionals actually explored patients' goals: The allocation of time in patient meetings indicated that the medical aspect of the professional logic was stronger: approximately four minutes out of an hour were devoted to conversation about 'What matters to you?' and patients' personal goals, while most of the time was spent by health professionals collecting medical information and setting physical goals for patients. The focus group discussions revealed that this professional logic dominated the market logic of choice described at macro-level: Patient participation was not represented as freedom of choice regarding service delivery. Often, negotiations relating to autonomy occurred.

Yes, oh yes, but the question is what is important to the patient. If he says 'It's important I get to rest before I go home,' should we still listen to the patient's wish, should we work according to the patient's wish or should we work against the patient's wish 'You have to exercise, you have to go through rehabilitation and make an effort,' and... it's not easy. (Nurse in focus group. Municipality 3, rural).

The goal-setting tools affected the structure and agenda of the ten meetings between health professionals and patients. Health professionals formulated the question 'What matters to you?' nearly verbatim as stipulated by the tools. Thus, the logics of state and profession written into the tools at the meso-level continued to dominate.

The focus group discussions revealed that the logic of state was dominant because patient participation in goal setting was mostly a means of planning how patients would manage at home. In addition, one clearly expressed norm was to distribute services equally to all patients out of the municipalities' standard set of

services. Sometimes, a mismatch occurred between the services available in a municipality and patients' preferences and what fit into their routines. In such situations, health professionals adhered to standardized care and valued a cooperative patient role. This bureaucratic approach can be associated with blended logics, specifically the value placed by the state on equal treatment and the managerial principles of cost-efficient care processes stipulated within corporate logic.

P4: Because we home care nurses don't have the time or space or capacity to treat people differently. We don't care whether you're a king or a hatter. You will get the help you need, what we can provide you with, what you need and what is important to you. (...) There is equal treatment. It doesn't matter who you are. You will get what you need.

P3: Same with us, too. (P4: nurse home care services, P3: Occupational therapist in reablement services. Focus group, municipality 1, city).

Moreover, the logic of family appeared to be suppressed by the dominating logics at this level. Health professionals frequently undertook negotiations with relatives. In focus group discussions of such situations, they appeared to be influenced by a cost-efficiency mindset in which relatives could assist in health service delivery (corporate logic); they perceived relatives as lacking the skills to assess patients' needs (professional logic) and often provided usual care instead of following relatives' preferences (state logic). All three of these three logics that dominated at the micro-level are bureaucratic, and they overpowered the logics associated with individualized services, namely those of family and community, which would have prioritized attending to patients' families or life stories, and the market logic of personal choice. A religious logic did not appear at the micro-level.

Our observations of how the tools developed at meso-level were used at micro-level and of the care-planning meetings and focus groups all indicated that health professionals adhered to three logics simultaneously in decisions about service delivery: health professionals' medical standards for how to handle symptoms of patients with multi-morbidity (professional logic), a state logic of bureaucracy, and a cost-efficiency principle imposed by a corporate logic. Other logics hardly appeared, even though there were a few instances of invitations to include the patient's individual goal in a more open way:

Meeting leader (head nurse): 'What is important to you?'

Patient does not respond; she continues: ‘What do you value right now? What should we be keeping in mind? Have you set any goals? Any wishes that could make the road ahead easier?’

Patient: ‘Difficult question to answer.’

Meeting leader: ‘Well, you can always think about it. (...). Is there something you are excited about or look forward to when you come home?’

Patient: ‘Play the pipe organ. And if I can get hold of some drawing materials.’

Meeting leader: ‘You draw?’

Patient: ‘No, I want to.’

(interprofessional meeting for an older man with multi-morbidity, rural municipality)

The constellation of logics at this level, in sum, constituted the following norm for patient participation: All patients should participate in making care processes efficient by setting goals to manage life at home.

#### Differences between health service levels

Within the normative integration process, the professional and state logics were strong and transcended levels. The relationship between these logics helped them strengthen each other and materialize bureaucratically. There were subtle nuances in the normative justifications for patient participation: Participation as conceived at macro-level entailed enabling older persons to live independently in the community as a matter of right, while participation at lower levels was conceived in terms of allowing patients to contribute to care planning that favored efficient care processes directed toward the goal of going home. The intervention at macro-level attempted to shift the content of the professional logic, but at micro-level its traditional medical focus in decision-making persisted.

Figure 2 summarizes the main findings. The normative justifications supplied within each logic differed between levels. The columns show how each of the seven institutional logics materialized at each level. At meso- and micro-level, multiple logics appeared only weakly, and three logics vanished. The rows show how the constellations of logics differed between levels. At macro-level multiple logics were in play, while the meso- and micro-levels were more similar to one another, applying fewer distinct logics. Logics with blue letters are associated with individualized service delivery and those with red letters with standardized service delivery.

#### Discussion

The results from our study show how normative justifications for patient participation are connected to different institutional logics and how constellations of logics vary between health service levels. The macro-level

white paper and guideline were associated with multiple cooperative logics, through which several areas of patients’ lives were conceived as relevant to goal setting (Fig. 2). Patient participation was justified by the idea that health services should make it possible for patients be the drivers of their own lives and live full, independent lives in their communities. Throughout the documents, we found attempted to strengthen the logics—family, community and religious logics and a market logic of choice—that promote individualization and to shift the professional logic from a medical to a person-centered conception (Fig. 2). However, the constellations of logics at the lower levels reflected an imperative to standardization rather than individualization. The meso-level operationalization of tools for practice reflected a state logic which focused bureaucratically on the idea that all patients should set goals for independence at home, while a professional logic specified medical means of achieving this end. Finally, health professionals at the micro-level adhered to three logics simultaneously in goal setting with patients: a professional logic focusing on medical goals, a state logic emphasizing the importance of equal treatment and a corporate logic prioritizing cost-efficient care processes in which patients set goals to manage life at home.

Our discussion will be centered around how the applied institutional logics formed different intervention goals. The normative justifications for patient participation representing either individualization or standardization is an overall finding. Individualization proposed at macro level is comprehensive and consistent with ideals of goal-oriented care, which attend to individual patients’ values, needs and preferences and take a holistic view of patients, their families and their contexts [6, 7, 13, 39]. The Norwegian health services are based on integrated care models which recommend going from traditional to individualized service delivery, by for example supporting patients by including their relatives, community and informal social network [7, 14]. Institutional logics of family and community could have been expected to appear more strongly at lower levels in our study. Weak appearance of the market logic may be explained by the fact that in Norwegian municipalities, the public health services are not strictly market-regulated because the municipal services often are the sole supplier [43]. However, the standardized approach that we found is in line with other studies. The professional and state logics were found to dominate the process of implementation of multi-professional chronic care [53]. Moreover, health professionals’ adherence to the medical professional logic and efficiency proposed by a corporate logic has been found in other contexts as well [34, 35]. One systematic review found that efficiency is a value that transcends the various levels of integrated services

	Family logic	Community logic	Religious logic	State logic	Market logic	Corporate logic	Professional logic
<b>Macro-level</b> <i>Intervention documents.</i> Towards a cooperative constellation of logics	Older person is family member; relatives involved in decision making.	Older person is member of community; involves context and life history.	Older person has existential needs and life values.	Older person is co-producer of service delivery, with rights and responsibilities.	Older person is consumer of services with freedom of choice.	Older persons' participation maintains their health, for cost-efficient services.	Older person is empowered to master personal goals.
<b>Meso-level</b> <i>Intervention tools.</i> Two dominant logics (state and professional)	Logic did not appear.	Logic appeared only weakly.	Logic appeared only weakly.	Tools plan transfer to home; participation to share responsibility for becoming independent.	Logic appeared only weakly.	Logic appeared only weakly.	Tools let patient participate in providing medical information.
<b>Micro-level</b> <i>Practices employed by health professionals.</i> Additive constellation of three dominant logics (state, corporate, professional)	Logic did not appear.	Logic appeared only weakly.	Logic did not appear.	Patient is an obliged co-producer of services with goal being to go home.	Logic did not appear.	Patients participate within the confines of efficient service delivery.	Patient participate in disease management.

**Fig. 2** Institutional logics of patient participation between levels of health services

[3] and which can be associated with standardization. This co-existence of principles of individualization with those of standardization which we found, and the conflict between them, is consistent with studies of competing institutional logics and of the challenges faced by health professionals in balancing these principles when encouraging older patients to participate in decisions about service delivery [55, 56].

Our findings of less person-centered approaches opposed those reported in Zonneveld and colleagues' Delphi study of values in integrated services, which identified empowerment and person-centeredness as the most important values at the micro-level and the least important at the macro-level [21]. We found that health professionals claimed to value person-centered care; however, this value was not fully reflected in their practices. Few studies have examined the connection between values and action in integrated health services [21]. A possible explanation for our findings of discrepancies between values and actions at micro-level could be that actors' values do not necessarily guide actions. Copeland [57] points out that it is not always best to follow guidelines, because the decisions health professionals make about whether to take a moral action must be weighed up in terms of potential consequences and utilities. Guidelines are not rules to be enforced in practice without considering contextual circumstances [57]. Other obligations in the situation, and especially dominating logics, could have led the health professionals to less often discuss individual patients' preferences, even

though the guideline requires it. Actors in health services can also manipulate and elaborate various logics to their own advantage [23]. The normative pressure may come from the professions themselves. The professional logic has traditionally been strong in decision-making [25, 27, 35]. The medical complexity of caring for older patients with several diseases [7] could lead to the tendency to adopt a standardized approach. Complexity in professional work is a task characteristic associated with standardization, because standardization maintains care pathway enactments by professionals [58].

Furthermore, institutional logics inform normative integration because constellations of logics form structures between health service levels which can enable or constrain action [53]. Logics can be a toolkit or a set of rule-like structures [25]. We interpreted the white paper as an attempt to make multiple logics equivalent and cooperative. This would provide health professionals with multiple available logics and increase their ability to exercise discretion and individualize service delivery [27]. However, at the micro-level, three logics had to be adhered to simultaneously in decision making. This situation allowed less space for health professionals' creativity and fewer opportunities to exert discretion like what may be beneficial in goal-oriented care, because the work task had to satisfy the demands of more than one logic simultaneously [53]. Actors' behavior is, at least in part, driven by the normative pressures of achieving the goals of the logics according to which they work [25]. Moreover, the dominant logics at the micro-

level were bureaucratic, and bureaucratic logics are known to be less generative of change [25]. Thus, the constellation of state, professional and corporate logics standardizes service delivery and forms a barrier to patient participation.

Knowledge of how normative integration functions is sparse but necessary to ensure integrated health services [18, 19, 21]. Knowing how institutional logics materialize can help us understand why the achievement of patient participation and normative integration in the intervention becomes difficult. This does not mean that we expected to find the same logics in play at each level, as different actors have different responsibilities and perspectives, and as logics are context-dependent [21, 25]. However, institutional logics guide actors' behavior and thus compete with the prescriptions of the intervention. This knowledge makes explicit the distance that exists between policy and practice and why it occurs: multiple goals and norms for practice are being produced through a range of institutional logics, which can hamper normative integration between levels of health services.

#### Study limitations and strengths

Our research suffers from limitations that can be addressed in future research. Firstly, implementation of the intervention started only 6–12 months before our data collection. The results need to be interpreted as issuing from an early phase of implementation; the intervention may be carried out differently at a later time. The selection of rehabilitation wards is a potential source of bias because these wards may have a stronger focus on self-management than long-term wards, which could have made bureaucratic logics more salient. Hence, the results are not representative for other work tasks of service delivery; neither do they necessarily indicate the logics that dominate at each level more generally or capture variations in the field. Patients and health professionals could possibly have behaved more collaboratively because they were being observed [48]. Constructivist analyses assume multiple interpretations are possible, and other researchers could have interpreted the text differently [48]. However, the overall conclusions of our study are in line with those of other studies. The strength of the study is that it generates knowledge by being theoretically informed by what happens when this kind of interventions are implemented. Thus, this study provides transferable perspectives by pointing out how goals for an intervention differ between levels of health services. Moreover, that the logics we found to dominate are consistent with those reported in other studies [35, 53] suggests transferability to other patient groups with chronic diseases.

#### Implications

This study illuminated differences in institutional logics and distance between policy goals and practices. There can be differences between policy goals and practices [15, 21], especially within integrated care contexts with network-based governance [21, 44]. In the present study, this entailed that actors themselves could develop intervention tools, and there were few formal regulations controlling their practices. This is an aspect for policy makers at the macro-level to consider. On the other hand, a central question that arises is whether the policy goals are too comprehensive to be carried out. There is a lack of evidence that ideals of integrated service delivery are implemented in contexts [13, 15]. The standardized approach is thought-provoking: it was the more bureaucratic logics that transcended levels. Hence, the extent to which the intervention made it possible for the older patients with multi-morbidity in this study to set the agenda for their individual service delivery was limited. To improve normative integration of the intervention, meso-level actors could perform user surveys to let patients assess the success of the intervention. Moreover, revision of the intervention tools so that they ask about several areas of patients' lives and contain more detailed prescriptions for health professionals could counteract the fact that multiple normative justifications influence how the intervention is carried out.

#### Conclusions

Normative integration was low within the intervention promoting patient participation in which older patients with multi-morbidity are encouraged to formulate individual goals for service delivery. Between the macro-, meso- and micro-levels of health services, values and actions were connected in different ways. Actors' normative justifications for patient participation differed both within each of the institutional logics and in terms of the constellations of logics between the various levels of municipal health services. These findings broaden the understanding of how multiple set of norms co-exist and guide action; they also draw attention towards the dynamics between logics. We observed a reduction in the number of logics in play between the three levels. When patients were asked to formulate individual goals for service delivery, norms and goals for the intervention shifted from individualization to standardization between levels. Even though health professionals were engaging in the goal-setting intervention, the comparatively few distinct logics guiding their actions meant that service delivery was still centered more on what matters to the health services than on what matters to patients. Overall, the findings regarding how vertical normative integration contributes to patient participation were disappointing for the case being studied. Still, knowledge of

institutional logics in services for patients with multi-morbidity provides a new theoretical frame that helps to understand why patient participation and integration of health services can be low. We hope that this line of sight will encourage further research on how institutional logics are reflected in professional work. More studies focusing on multiple institutional logics and multiple levels of health services could inform the normative integration which is necessary to integrated service delivery interventions.

### Supplementary Information

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**Additional file 1.** Interview and observation guide

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### Authors' contributions

All authors designed the study. JDO collected the data. RK and MS were co-moderators of the focus group discussions. JDO conducted the analysis in collaboration with RK, and MS and TA regularly contributed in analysis discussions. JDO wrote the draft, and all authors contributed in manuscript revisions. All authors read and approved the final manuscript.

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### Availability of data and materials

The data generated and analyzed in the current study are not publicly available due to Norwegian privacy legislation and the form signed by the participants and municipalities about the study's privacy. The data generated are available from the corresponding author on reasonable request.

### Ethics approval and consent to participate

The Regional Committees for Medical and Health Research Ethics (ref 2018/852/REK midt) waived the need for approval for the study. The Norwegian Centre for Research Data approved the study (project number 60524). The health professionals, patients and relatives who attended the meetings received oral and written information about the aim of the study and assurance that participation was voluntary and that they could withdraw from the study at any time without duty to explain why. Written consent to participate was obtained from all participants. At the last inter-professional meeting, two health professionals did not want the meeting to be audio-recorded, and this request was honored. They were not asked to justify why. To prevent the four municipalities from being identified, we anonymized the material and have not referred to the municipalities' public websites.

### Consent for publication

Not applicable.

### Competing interests

The authors have no competing interests.

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# Paper II



RESEARCH ARTICLE

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# Sharing responsibility: municipal health professionals' approaches to goal setting with older patients with multi-morbidity – a grounded theory study



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## Abstract

**Background:** Recent health policy promoting integrated care emphasizes to increase patients' health, experience of quality of care and reduce care utilization. Thus, health service delivery should be co-produced by health professionals and individual patients with multiple diseases and complex needs. Collaborative goal setting is a new procedure for older patients with multi-morbidity. The aim is to explore municipal health professionals' experiences of collaborative goal setting with patients with multi-morbidity aged 80 and above.

**Methods:** A qualitative study with a constructivist grounded theory approach. In total twenty-four health professionals from several health care services in four municipalities, participated in four focus group discussions.

**Results:** Health professionals took four approaches to goal setting with older patients with multi-morbidity: motivating for goals, vicariously setting goals, negotiating goals, and specifying goals. When 'motivating for goals', they educated reluctant patients to set goals. Patients' capacity or willingness to set goals could be reduced, due to old age, illness or less knowledge about the health system. Health professionals were 'vicariously setting goals' when patients did not express or take responsibility for goals due to adaptation processes to disease, or symptoms as cognitive impairment or exhaustion. By 'Negotiating goals', health professionals handled disagreements with patients, and often relatives, who expected to receive more services than usual care. They perceived some patients as passive or having unrealistic goals to improve health. 'Specifying goals' was a collaboration. Patients currently treated for one condition, set sub-goals to increase health. Patients with complex diseases prioritized one goal to maintain health. These approaches constitute a conceptual model of how health professionals, to varying extents, share responsibility for goal setting with patients.

**Conclusions:** Goal setting for patients with multi-morbidity were carried out in an interplay between patients' varying levels of engagement and health professionals' attitudes regarding to what extents patients should be responsible for pursuing the integrated health services' objectives. Even though goal setting seeks to involve patients in co-production of their health service delivery, the health services' aims and context could restrict this co-production.

**Keywords:** Health care delivery, integrated, Co-production, Collaborative goal setting, Health professionals, Multi-morbidity, Aged, 80 and over, Conceptual model

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## Background

Recent health policy promoting integrated care emphasizes that health professionals and patients can co-create value when patients participate in formulating how their own health services should be delivered. Health professionals should, therefore, to a greater extent, collaborate with older patients when planning their care [1–3]. The number of persons over 80 years of age is increasing, and multi-morbidity, which is having two or more chronic diseases, is frequent in this group [4–7]. Health-care for patients with multi-morbidity often comprises care from several services, from multidisciplinary health professionals, and from several clinical guidelines. Often, older patients experience functional decline and receive complex care over a long period of time. The goal for the care these patients receive is not always unified across care settings, where variation in goals between the health professionals involved, as well as between health professionals and patients, may occur [3–6, 8–10]. In order to resolve discrepancies between the opinions of patients and those of health professionals regarding health care delivery, it is recommended in national clinical guidelines for people with multi-morbidity that they should have the opportunity to collaborate with health professionals to formulate goals for own care [11, 12]. However, little is known about how health professionals initiate and practice collaborative goal setting with patients with multi-morbidity [13, 14].

Integrated care are structured efforts to provide coordinated, pro-active and multidisciplinary care, which is centred around individual patients' preferences [1–3]. When health professionals add patients' preferences in decisions about health service delivery, the services are co-produced [1]. Co-production at the individual level, is a collaborative process in which health professionals and patients share mutual information and define strategies for dealing with illness [15, 16]. A reciprocal contribution to co-production occurs when patients take greater responsibility for and actively collaborate in planning their own care, while health professionals involve and support patients to manage chronic conditions in daily life, based on the patients' own values, preferences, and needs [1–3, 17, 18]. Through co-production, additional value is co-created [15, 16]. The primary value is improvement of the patient experience of service delivery. A secondary value is the reduction in the utilization of care services that can be achieved when health services help patients to live more independently [16, 19]. However, engaging older patients with multi-morbidity to actively collaborate with health professionals may be challenging due to their frail health, the changing severity of their diseases, and their complex care needs [2]. Previously, health professionals only to a limited extent have collaborated with patients on what matters to them [2, 20].

To overcome such difficulties, a specific form of collaborative goal setting has been suggested in order to attend to patients' preferences and needs in the co-production of service delivery. Collaborative goal setting is 'a process by which health professionals and patients agree on a health-related goal' ([13], [20], p., 2). A health professional asks the patient to express needs and goals for care delivery according to the patient's own definition of health. Goal setting can be carried out each time the patient receives a new health service in the care pathway [21]. The patient's goals can be related to disease symptoms, physical functioning, or well-being; they can also be social goals or goals related to values of life [20].

Goal setting is a complex interactional activity in which health professionals play an important role [22]. A review indicates that health professionals perceive that goal setting increases collaboration with patients [8]. However, the process of negotiating and formulating specific goals is a challenging one, in which health professionals see a need to educate patients to succeed [23–25]. They perceive that the articulation of goals does not come naturally to all patients [23]. Health professionals are reserved about involving patients whom they perceive to be unmotivated or to be taking less responsibility for setting goals [8, 26], who have problems with communication or cognition [8], or who are perceived as less able to set goals [27]. Consequently, health professionals may perceive they should control goal setting by excluding specific patients or specific psychosocial goals in order to responsibly implement their professional knowledge as well as to respect time pressures and financial constraints [8, 26–29]. Palumbo [15, 19] suggests that co-destruction rather than co-creation of value can occur: the parties can be unaware of the clash of their interests or deliberately struggle to achieve benefits from the service provision. If the parties do not share common goals, their interactions do not co-create any additional value for patients in service delivery [15, 19].

There is limited research on goal setting for patients with multi-morbidity across settings [13, 14]. Previously, goal setting has been studied within neurological, rehabilitation, and in-patient settings [8, 9, 13, 26]. According to integrated care models, many Norwegian municipalities are implementing a procedure of goal setting in health care delivery for older patients [12]. Even though research exists on how health professionals carry out goal setting [23–28], few studies have conceptualized this for older patients in the municipal settings [13, 14], which have a health policy promoting co-production [1]. The aim of this study was to explore municipal health professionals' experiences of interacting with patients with multi-morbidity aged 80 and above in collaborative goal setting.

## Methods

### Design

To explore health professionals' experiences of interacting with older patients, a qualitative study using a constructivist grounded theory approach is particularly suitable [30]. Constructivist grounded theory focuses on actions and interactions, aiming for an abstracted understanding of experiences [30]. Constructivist grounded theory views the analysis as located in time, place, and situation [30], which is preferable when studying goal setting within a municipal context. We chose focus groups because we aimed to explore the experiences of a particular group in relation to a defined subject [31]. The interaction in focus groups can generate rich data by encouraging participants to explore and clarify individual and shared experiences and perspectives [31]. In constructivist grounded theory, the analysis begins after the first interview [30]. The application of this method allowed us to explore goal setting progressively by adapting subsequent focus group discussions in light of findings from earlier ones.

### Setting

#### *The Norwegian context*

In Norway, municipal integrated care for older people includes rehabilitation and long-term care, which takes place in community hospitals for rehabilitation, in nursing homes, or in patients' homes. Patients can also receive reablement, which is a time-limited and intensive rehabilitation service delivered in patients' homes. Reablement aims to improve patients' physical abilities and maximize independence [32]. The amount and kind of services individual patients receive from municipal health services following a hospital stay is decided by an office for allocation of services (using a purchaser-provider model) or by municipal health service managers. Decisions are based on health professionals' assessment of the patient's functional level. Following the assignment of services to the patient, health professionals involve patients in discussions about how the services will be delivered [33]. Health professionals in municipalities who work with older patients often comprise nurses, auxiliary nurses, one physician, one physiotherapist, and an occupational therapist. These health professionals work in institutions or in patients' homes. Patients aged 80 and over stay an average of 15 days in short-term or rehabilitation wards. They can receive four weeks of rehabilitation support in their homes [34]. Some patients transfer directly from the hospital to home, with or without home care services.

#### *Study setting*

The municipalities included in this study had implemented the goal setting procedure 'What matters to

you?' [14] for 6–12 months prior to the focus group discussions. The procedure is a consultation in which a health professional identifies a patient's goal for follow-up care in the municipality after hospital discharge [14, 35]. A goal is collaboratively set and documented for both the patient and the team of health professionals to work towards [21]. The procedure was implemented for all patients eligible for municipal health care. This study includes two rural (2000–3000 inhabitants) and two urban municipalities (with 40,000 and 70,000 inhabitants, respectively) in Western Norway. In each municipality, we included health professionals from several services: community hospital wards, rehabilitation wards, short-term wards in nursing homes, reablement teams, offices for allocation of services, and home care services.

### Recruitment and sample

The health professionals were purposively selected to represent a variety in occupations working in different clinical settings. Moreover, participants were eligible if having experiences with initiating goal setting by asking patients 'What matters to you?'. They were recruited by a manager in each municipality, who invited health professionals to a focus group discussion in their workplace. In total, 27 participants were invited, but 3 did not attend due to illness. Each of the four groups consisted of 5–7 participants, for a total of 24 health professionals, including head nurses in nursing homes (4), head nurse in home care services (1), nurses (7), caseworker (1), auxiliary nurses (3), occupational therapists (2), physical therapists (4), physician (1), and one person without health education (1). Two of the focus groups had a male participant; the rest of the participants were females. Regarding their age, 5 of them were between 20 and 30 years old, 10 were between 30 and 40, 4 were between 40 and 50 and 5 were 50–65 years old. Their work experience within this area ranged from 6 months to 30 years.

### Data collection

We conducted four focus group discussions from September 2018 to February 2019. The focus groups took place without interruption in meeting rooms within participants' workplaces. A semi-structured interview guide contained questions prompting health professionals to describe and discuss clinical situations they had experienced of goal setting for patients aged 80 and above after hospital stays. ([Additional file – Interview guide](#)). The discussions lasted approximately 90 min. They were audio recorded and later transcribed verbatim and anonymized by the first author. The first author wrote field notes and observations about the interactions in each group. We analyzed data after each interview. From the categories generated by our ongoing analysis, we derived

theoretical sampling questions and added these to the interview guide for subsequent focus groups [30].

**Data analysis**

Constructivist grounded theory explores processes as well as actions and interactions [30]. We used patient involvement as a sensitizing concept [30], which means that how health professionals experienced to involve patients, served as a point of departure for our analysis of health professionals’ interactions with patients. The concept patient involvement did not define or delimit how the data would be coded. In the initial coding, we divided the focus group data into small units and coded to explore health professionals’ actions [30]. Then, in focused coding, we merged initial codes that were similar and concentrated on frequent and significant codes. By the constant comparison method, we tested these codes against the rest of the data to develop the categories [30]. The categories related mainly to characteristics of patients, levels of collaboration, and how the municipal context influenced actions. The software NVivo version 12 supported focused coding. Table 1 shows an example from the coding.

Through theoretical coding, categories relating to one another and accounting for the data were included in a conceptual model [36] of approaches to goal setting. Memos were written throughout the process of analysis to guide and record the analysis [30]. Constructivist grounded theory recognizes the researcher as situated within the research process and acknowledges that several interpretations of the data are possible [30]. Thus, the authors, who come from different disciplinary backgrounds, discussed the interpretations regularly. We found that the fourth focus group validated the categories from the analysis of the first interviews. Due to this saturation in the categories [30], four focus groups were considered enough for development of the concept within this study.

**Results**

Overall, health professionals considered their new goal setting method to be more patient-centered and meaningful than their earlier practices. Often the patient’s main goal was to return home and recover health. In

long-term wards in nursing homes, goals more often related to well-being than recovery. Patients’ relatives were not included in goal setting as a routine, but relatives often expressed their opinions about the goals. The realization of an ideal model of goal setting, could be hampered by shortcomings of both the health services’ ability to tailor services to each patient, and older patients’ capacities to collaborate in the goal setting process. Health professionals’ practices for goal setting with older patients with multi-morbidity comprised four approaches:

**Motivating for goals**

Health professionals discussed that some patients could not immediately articulate goals and needed introduction to the goal-setting mindset before they could collaborate with health professionals in goal setting. They educated these patients to take an active role in order to meet health services’ expectations regarding the setting of goals. Moreover, they provided information to patients about services that might help them attain their goals or remain independent. Some patients were passive in goal setting. Health professionals found that older patients were not used to being asked about their preferences regarding health care, wanted to leave decisions to health professionals, or found goal setting difficult.

“They aren’t used to thinking along those lines. Like when we brought in this questionnaire, some people kind of shut down. They didn’t know how to answer, didn’t know, ‘Oh, heavens, I don’t know about that, no, you have to answer that one’ (*laughs*)”.  
(Nurse at nursing home, Group 3)

Some patients appeared to have the mindset that they had reached a turning point in their age, so that setting rehabilitation goals no longer felt appropriate or like it should be their responsibility. Moreover, some had limited understanding of the current health system.

“Those over 80 are familiar with the old healthcare system, where you stayed at the hospital and you got well. There’s a lot of confusion surrounding the

**Table 1** Coding from quotes to category

Quotation	Initial coding	Focused coding	Category
‘Some say, for example, that it is important for them to be able to walk and then we see that it is unlikely, we cannot take away their hope. Because then they may not want to be with us or lose all motivation. But we try in a way to orientate on something that is achievable while they are with us, for example to be able to go with aids or other things that may be important to them.’ (Occupational therapist, Group 1)	Perceiving the goal as too ambitious		
	Calculating consequences of addressing it		
	Reality-orientating	Reality-orientating	Negotiating goals
	Adjusting the goal downward		



current system. After one or two nights as an in-patient they get discharged to the municipal health services.” (Physical therapist at rehabilitation ward, Group 4)

Health professionals discussed expectations regarding the patient’s role of being active in the rehabilitation process, as the services demand patient effort. They explained to patients the scope for goals and that there would be municipal health services available to assist them towards their goals. Simultaneously, they asked, ‘What matters to you?’ and expected patients to collaborate.

“With those who aren’t motivated—those who aren’t used to thinking that way—with them it’s very important that you try to be a part of their journey and say, ‘What is important to you?’ To try to make clear ‘How will you reach that goal, or what’s important? How will you achieve that?’.” (Physical therapist at rehabilitation ward, Group 4)

Patients were encouraged to set goals such as managing to live in their own homes instead of in an institution. Some patients were tired and less motivated after prolonged illness. Some were reluctant to go home and needed support to focus on their own resources:

“It’s important to focus on what the patients can do on their own, because they’re very—especially after a hospital stay and if they are over 80, then we see it even more—they are very apprehensive, have very little confidence about coming home and have a lot of thoughts about it, and have imagined different scenarios in their heads.” (Physical therapist in rehabilitation, Group 1).

If explaining expectations to patients did not encourage them to collaborate, health professionals set a rehabilitation goal that was earlier than what the patients felt ready for because they had to keep within the timeframe of the service the patient had been allocated. Furthermore, they refrained from performing tasks for patients that they knew the patients were able to perform themselves in order to help patients understand that they were responsible for doing their part. This felt like a dilemma. To encourage reluctant patients to set goals, health professionals needed a uniform culture among staff regarding patient self-management. When some of the staff did not acknowledge the benefits of support for self-management, they did not expect patients to have such goals. Through giving patients time to consider and expressing empathy for their situations,

health professionals found that when patients grasped the mindset, they became motivated to collaborate in goal setting and to perceive the goals as their own.

#### Vicariously setting goals

For some patients, health professionals set goals vicariously. At the point when goal setting should have taken place, some older patients with complex needs neither articulated any goals nor made explicit their need for help. These patients’ preferences and needs, or the key factors that could improve their situations, remained unknown. Some patients were ‘in their own foggy world’ because of disease symptoms, such as apathy related to exhaustion, depression, or cognitive impairment. Such symptoms led to challenges for communication. Other patients were in a process of adapting to their disease and so were not ready to set goals or receive help. Some patients covered up their need for help to maintain their social status as independent. Two participants in focus group 2 discussed these issues:

“P6: Particularly people who are so old they don’t want to be a burden on anyone, they want to manage on their own and might conceal their needs.

P1: Either that or they were highly functional people before they became ill. We have a patient like that, a woman with advanced Alzheimer’s who is currently receiving no services. We have tried to go in there but are met with a closed door, ‘No, I don’t want anything’.” (P6, worker without health education, and P1, head nurse, home care services)

Health professionals could not carry out the goal setting procedure in the standardized way with patients whose disease symptoms dictated that they could not take responsibility for setting goals. To elicit what mattered to patients, health professionals identified patients’ problems by establishing a trusting relationship. This meant they were present, observed patients and their surroundings, and got to know them. They also collaborated with patients’ relatives to obtain more information. Subsequently, they set goals vicariously for these patients that they judged might be reasonable for their conditions, for example for a patient with dementia.

“P1: So when she went home with GPS [Global Positioning System] soles in her shoes, it was with her family’s blessing (...)

P2: I think that was important to her.

P1: Yes, it is. And she loves that freedom.” (P1, head nurse, and P2, nurse, home care services, group 1).

In other cases, health professionals deferred goal setting until the symptoms that hampered communication diminished. However, health professionals' attitudes towards the possibility of involving patients with cognitive impairment varied, as did the amount of time they made available. Thus, their efforts varied, and they excluded some patients by not seeking to elicit their goals. For these patients, applying the goal setting procedure in the health services did not change the levels of collaboration compared to past practices.

### Negotiating goals

Sometimes agreement on goals was challenging to obtain, because health professionals and patients had differing expectations about what the goal should be and who should be responsible for its attainment. Patients, and frequently relatives, expected more services than health professionals considered to be usual or necessary in such a case. Patients' adult children, in particular, frequently interrupted the goal setting by asking for additional services for their kin. They typically felt it would be safer for the patient to stay in an institution, while the patient wanted to live at home. Unrealistic expectations could also occur when patients expressed goals for improving their health that health professionals judged to be physically unachievable or inappropriate to the timeframe.

“Interviewer: Do they need some help identifying the type of goal they can have?”

P2: They might. For instance, some say it's important for them to get up and walk, and if we see that that is unlikely, we still can't take the hope away from them. Because then they might not want to be with us, or they lose all motivation. But we try to focus on something that would be achievable during the time they are with us, like being able to walk with a mobility aid or whatever else might be important to them.

P3: Same with us, we have a fairly short time frame in that we have four intensive weeks, so it's a bit limited what can actually be achieved.” (P2, occupational therapist in short-term ward, and P3, physical therapist in reablement, Group 1)

The approach taken by health professionals to negotiations was, firstly, to consider the extent to which adjusting the goal downward (i.e. towards the patient receiving fewer services) by clarifying expectations would reduce the patient's will to collaborate. To tell patients that their health goals were too ambitious felt like a dilemma and uncomfortable because this could shatter their hope. Next, health professionals initiated a dialogue to negotiate with patients and, if appropriate, relatives. The

approach to this dialogue varied from mentioning which services were available to an explicit negotiation dialogue, which felt like conducting a reality orientation about how the health system worked. Clarifying early in the care pathway the services available could prevent such confrontations. Negotiations felt justified, because resources were allocated to benefit all patients. Furthermore, it was considered legitimate to exclude relatives' preferences, since the goal setting procedure was designed to weight patients' autonomy over relatives' opinions. Challenging negotiations with patients' children sometimes remained unresolved. With patients, on the other hand, health professionals usually converged on a mutually acceptable goal.

“P6: It was suggested we at least meet half-way (...)

Interviewer: And did everything work out for that person?

P6: I don't know yet. Guess we're not quite there yet.

P1: I suppose it's about finding the second-best solution, something we can all live with.” (P6, worker without health education, and P1, head nurse at home care services, Group 2)

### Specifying goals

Health professionals agreed with some patients on their main goals and assisted them in specifying them. In cases of less complexity, the goal and how it should be specified was often easy to define. In other cases, health professionals adopted the approach to goal setting mentioned previously, which led to a goal being specified. Patients' goals were often to recover or maintain functional abilities and independence. Such goals were in line with the municipal health services' objectives and made collaboration easier. However, health professionals perceived patients' goals as diffuse when they contained no specific actions for attainment.

“It is not very specific goals, I think. It's either getting better or coming home.” (Physician at short-term ward, Group 4).

A goal of going home could be specified through sub-goals like physical exercises and necessary aids for patients to be safe at home. Health professionals set the sub-goals to plan how the team and the patient could work towards the patient's goal. They perceived the process as collaborative and on the patients' terms. Premises.

“It's just helping them to see there are some steps on the journey.” (Physical therapist at rehabilitation ward, Group 4).

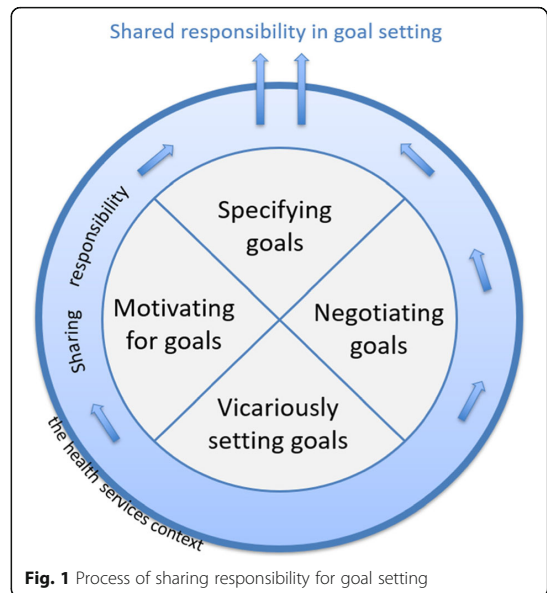
To specify patients' goals, some used goal-setting instruments to help patients reflect on important areas of life within which they could set self-management sub-goals. Health professionals specified these goals both to be motivating for patients and to match the municipal context within which the team worked. When a patient had several diseases, which led to several or conflicting goals, health professionals set aside their own opinions about what to do and clinical guidelines and collaborated instead on what mattered to the patient. To direct resources in response to patients' preferences could simultaneously facilitate health professionals' rationing of care.

"It's so important that the resources are spent on what the user thinks is important. We might have a user with kidney failure and we think, 'Well, we need to start dialysis then, that's clear,' and so on. But for them, that might not be important at all. They want to stay at home as long as possible and have peace and quiet, not travel to the hospital three times a week. Being free of pain, help them feel safe and confident and such, and their focus might be something completely different from what we were thinking." (Head nurse at home care services, Group 3).

For patients who were discharged early from hospital, goal attainment was unpredictable due to their unstable health and risk of getting worse. In such cases, health professionals involved patients' relatives in supporting them to feel safe at home or to do their rehabilitation exercises in order to attain the goals. Patients with serious diseases could not set goals of maintaining health. For these patients, goals were set within the domains of well-being and values, according to the practices of advanced care planning and palliative care.

### Sharing responsibility for goal setting

The core category which contributes to understanding why different approaches were taken to goal setting is health professionals' sharing of responsibility between patients and the health services. Shared responsibility means that the parties collaborate to agree on goals and contribute within their capacities to attain them. In working with patients whom they perceived as unable to take responsibility for goal setting, health professionals took the 'vicariously setting goals' approach (Fig. 1, bottom). The approaches of 'motivating for goals' and 'negotiating goals' were taken to transfer responsibility for goal setting to patients. This could enable patients to collaborate in the process of specifying goals. 'Specifying goals' (at the top of the figure) was the approach taken with the patients perceived as most active, with whom



**Fig. 1** Process of sharing responsibility for goal setting

responsibility was most easily shared. The arrows in the figure illustrate the process of sharing responsibility, in which health professionals elicited a commitment from patients to use their own capacities to maintain their health and simultaneously negotiated regarding the contribution the municipal services could make to goal attainment.

These approaches involved an interplay between patients, health professionals, and the health services context. The attitudes of health professionals and the criteria for goal setting varied in wards and contexts. The process was dynamic, and several conversations could occur before a goal was formally defined. Health professionals could draw upon several of the four approaches simultaneously, use the approaches to varying extents, and change approaches. The desired outcome was shared responsibility and agreement on goals.

### Discussion

Collaborative goal setting is a new intervention within integrated care for patients aged 80 and above with multi-morbidity. Health professionals play a vital role in determining how it is implemented and carried out in the health care services. By developing a conceptual model for goal setting approaches, this study adds to existing evidence presenting the four approaches health professionals took to goal setting: motivating for goals, vicariously setting goals, negotiating goals, and specifying goals (Fig. 1). Through these approaches, health professionals shared the responsibility for goal setting with patients. These approaches occurred in an interplay

between characteristics of patients, health professionals' attitudes, and the health service context for the goal setting.

Older patients with multi-morbidity have specific characteristics that must be considered in the process of goal setting [2, 20, 23]. In this study, health professionals perceived patient engagement to be a starting point for goal setting. Patient engagement varied, due to age-related functional decline, unpredictable disease symptoms, and because the older generation lacked knowledge of the health system. Previous studies indicate that health professionals perceive that some patients with multi-morbidity do not naturally articulate goals [8, 23, 26] and that it takes effort to engage them [8]. Health professionals motivate and negotiate goals with patients with single diseases [23–25]. For patients with cognitive impairment, health professionals have previously been found to set goals vicariously [37]. In the present study, health professionals were found to use all these practices, motivating, negotiating, and setting goals vicariously for elderly patients with multi-morbidity. Few studies have reported high levels of patient participation in goal setting [8, 38]. Health professionals' perceptions that these patients do not wish to be involved are contrary to research showing that older people with multi-morbidity in community settings prefer to participate actively, although, admittedly, to a lesser extent when they have four or more conditions [39]. In our study, health professionals found it easier to set goals with patients with less complex needs; for these patients they used the approach of 'specifying goals'. Patients' readiness to be involved, their motivation, and the extent to which they take responsibility, are prerequisites for co-creating care that matters to patients [1, 16, 17].

Facilitating co-production of care that aligns with patients' formulated goals is emphasized as a strategy in current policy on integrated care [1]. Health professionals in the present study and in other studies perceived their practices as being more oriented towards patients' preferences after they had begun to set goals with them [8, 35]. However, health professionals argued they needed to be in the driving seat of goal setting. This is in line with studies showing that health professionals tend to align goal setting with perceived responsibilities towards the system or medical knowledge [8, 28]. A new, related finding is that the challenges they experienced in motivating patients to adopt their goals, were related to differing perceptions as to whether patients were responsible for setting goals. Health professionals and older patients had conflicting perceptions of whether patients had reached a turning point in old age after which rehabilitation goals were no longer appropriate to set. Patient participation is often less sought by patients in the acute phase of illness and by patients who have several conditions [8, 39], a finding which this study confirms.

The objectives of integrated care include maintaining older patients' health, increasing the quality of their care experience through goal setting, and reducing care utilization by having health professionals support patients to live in the community [1, 17]. The health professionals studied here worked towards these objectives, which could, in practice, conflict. They held the attitude that patients' goals were not always realistic given the limitations in the health service system. Hence, the goals were partly pre-defined by health professionals, to suit the limited timeframe of municipal health services and the objective of maintaining patients' health in order to allow them to manage at home. Thus, there is a risk that responsibility for the attainment of the health services' goals for independence could be transferred to individual patients [40], possibly against the will or capacity of older patients with multi-morbidity. When health professionals and patients disagree on the desired outcomes of service delivery, co-destruction rather than co-creation of value is likely to happen [15, 19].

#### Implications for policy and health services

The current intervention for collaborative goal setting is introduced to enhance patient participation, service outcome and satisfaction with service delivery. However, the potential conflicts which can occur in such goal setting, should be considered in future health policies. Current health reforms aim to move care for complex patients out of hospitals [17], increasingly aiming for ageing in place and care and treatment in the municipal context. Following, conflicts in goal setting could increase in the future. Also, by the increased focus on activity and reablement, goal setting instruments could increasingly transfer responsibility for outcomes of service delivery to patients. This will be an unintended consequence of the health political objectives of co-production of service delivery. As shown in this study, health care professionals spend a lot of time on the collaborative goal setting intervention, both conducting the structured conversation with patients, as well as documenting and following up the goals. To conclude whether this goal setting is worth spending professional time on, more studies are needed. Both quantitative studies examining the level of patient participation in goal setting models should be performed, as well as studies focusing on the potential changes in service delivery, service outcome and patient satisfaction following the new practice. In times when health care professionals are becoming a limited resource, implementation of time-consuming interventions should be followed by evaluation of their effects. In Norway, as in other countries, effect studies of interventions in municipal health services are limited and sought for [41].

This study has two implications for health services. Firstly, the conceptual model of approaches to goal

setting created here, could be used in education and clinical settings, for health professionals to increase reflections and consciousness about how to tailor goal setting to the diverse group of patients with multi-morbidity, and on the extent to which patients should be given responsibility for determining their goals and the care services they need. Secondly, at the health service system level, our findings indicate that even though clinical guidelines to increase participation for patients with multi-morbidity is developed [1–3, 11], the goal setting tools used in clinical practice could be further developed to specify different approaches, that account for patients' level of disease severity and ability for participation. Further research could refine our model of four approaches to goal setting in other health service settings. Moreover, other possible mechanisms than sharing responsibility, which also may influence the goal setting, could be explored.

#### Limitations of the study

Few situations in which patients were excluded from goal setting were described. This could be since the participants were interviewed in a group with colleagues, and six participants were in groups with their managers. In two of the groups, participants had been asked by their managers to participate, and we do not know whether the most positive workers were chosen. These factors could have led participants to describe their efforts to involve patients in a more positive way. Furthermore, health professionals demonstrated a strong focus on setting goals for independence. Three-quarters of the participants worked within rehabilitation services. Therefore, the results may be less transferable to long-term services in nursing homes, since goals in those contexts can cover other dimensions, such as well-being [20]. We do, however, suggest that the results provide a general perspective for understanding goal setting, for the increasing and fragile group of older patients with multi-morbidity, both across countries and different care settings.

#### Conclusions

In collaborative goal setting with patients aged 80 and above with multi-morbidity, municipal health professionals to a varying extent shared responsibility for service delivery with each patient. To agree on goals, health professionals took four approaches: motivating for goals, vicariously setting goals, negotiating goals, and specifying goals. Goals were co-produced in an interplay of patient characteristics that influenced their engagement and health professionals' attitudes regarding who should be responsible for goal setting. Health professionals' processes of sharing responsibility with patients reflect the ambiguous objectives of both improving patients' perceptions of

quality of care and reducing care utilization, which is found in health policy and municipal health services. These ambiguous objectives for goal setting could lead to reduced collaboration on what matters to patients and ultimately circumscribe the role of the patient in co-producing service delivery.

#### Supplementary information

Supplementary information accompanies this paper at <https://doi.org/10.1186/s12913-020-4983-3>.

**Additional file 1.** Interview guide.

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#### Authors' contributions

JDO, RK, MKRS and MS participated in designing the study. JDO conducted the interviews, and RK and MS were co-moderators. JDO conducted most of the analysis, which JDO, RK, MKRS and MS discussed regularly. JDO wrote the draft, and RK, MKRS and MS contributed to manuscript revisions. JDO, RK, MKRS and MS read and approved the final manuscript.

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#### Availability of data and materials

The data generated and analyzed in the current study are not publicly available due to Norwegian privacy legislation and the form signed by the participants about the study's privacy. The data generated are available from the corresponding author on reasonable request.

#### Ethics approval and consent to participate

The health professionals involved received oral and written information stating that participation in the study was voluntary and that they could withdraw from it at any time without duty to explain why. Written informed consent was obtained from all participants. The Norwegian Centre for Research Data approved the study (project number 60524). The Regional Ethics Committee waived the need for approval for the study (ref 2018/852/REK midt).

#### Consent for publication

Not applicable.

#### Competing interests

The authors declare that they have no competing interests.

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# Paper III



RESEARCH ARTICLE

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# Games of uncertainty: the participation of older patients with multimorbidity in care planning meetings – a qualitative study



Jannike Dyb Oksavik<sup>1\*</sup>, Marit Solbjør<sup>2</sup>, Ralf Kirchhoff<sup>1</sup> and Maren Kristine Raknes Sogstad<sup>3</sup>

## Abstract

**Background:** Active patients lie at the heart of integrated care. Although interventions to increase the participation of older patients in care planning are being implemented in several countries, there is a lack of knowledge about the interactions involved and how they are experienced by older patients with multimorbidity. We explore this issue in the context of care-planning meetings within Norwegian municipal health services.

**Methods:** This qualitative study drew on direct observations of ten care-planning meetings and an interview with each patient right after the meeting. Following a stepwise-deductive induction approach, the analysis began inductively and then considered the interactions through the lens of game theory.

**Results:** The care-planning interactions were influenced by uncertainty about the course of the disease and how to plan service delivery. In terms derived from game theory, the imaginary and unpredictable player 'Nature' generated uncertainty in the 'game' of care planning. The 'players' assessed this uncertainty differently, leading to three patterns of game. 1) In the 'game of chance', patients viewed future events as random and uncontrollable; they felt outmatched by the opponent Nature and became passive in their decision-making. 2) In the 'competitive game', participants positioned themselves on two opposing sides, one side perceiving Nature as a significant threat and the other assigning it little importance. The two sides negotiated about how to accommodate uncertainty, and the level of patient participation varied. 3) In the 'coordination game', all participants were aligned, either in viewing themselves as teammates against Nature or in ascribing little importance to it. The level of patient participation was high.

**Conclusions:** In care planning meetings, the level of patient participation may partly be associated with how the various actors appraise and respond to uncertainty. Dialogue on uncertainty in care-planning interventions could help to increase patient participation.

**Keywords:** Multimorbidity, Delivery of health care, integrated, Patient care planning, Patient participation, Game theory, Uncertainty, Goal-oriented care

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## Introduction

Older patients with multimorbidity, suffering from two or more chronic diseases, often have complex health care needs [1–3]. This complexity means that goals for the services patients receive are not always unified among actors, nor do they always align with patients' own preferences [1, 4, 5]. Furthermore, patients' decision-making abilities tend to decline with age and the cumulative effects of long-term diseases which presents challenges for achieving patient participation in care planning [1, 6]. Nevertheless, person-centered, integrated care is the gold standard for service delivery, even when achieving it may be challenging [7, 8]. Integrated care is a structured effort to provide coordinated, proactive, multidisciplinary, and person-centered care [2, 9, 10]. Person-centered care can be operationalized through goal-oriented care, in which health professionals and patients identify and discuss what matters most to patients and align the goals for care with patients' preferences, values, and needs [8, 11, 12]. Patients' goals may relate to reducing symptoms or improving physical functioning or well-being; they can also have social dimensions or reflect life values [5, 8]. Goal-oriented care planning is assumed to increase patients' self-management abilities, health maintenance, and experience of care quality [1, 5, 11, 13].

However, the delivery of integrated care in general, and the achievement of patient participation in care-planning meetings in particular, is yet to be optimized. Older patients generally wish to participate more than they are allowed to do [14, 15]. Patients have reported a range of facilitators of and barriers to participation [16, 17]. The readiness of patients with multimorbidity to participate depends on, among other things, their physical and emotional strength and support from relatives [17, 18]. Patients may lack knowledge about goal setting, the rehabilitation process, and their condition; consequently, they can feel too disempowered to participate [4]. Patients have also reported difficulties in interacting with health professionals, including unsupportive attitudes regarding their beliefs and abilities related to care management, lack of information, and disagreements about the plan of care [17]. Health professionals and patients interpret and frame health problems differently [1]. What is more, health systems are changing to favor shorter hospital stays, with more services delivered in patients' own homes [19]. Patient participation can be challenging, additionally, when care planning occurs early in a patients' illness trajectory because some patients have less desire to participate when their conditions are acute and they have a higher number of diagnoses [4, 6]. Following acute illness, patients' preferences may also change [20].

Patients' experiences of multimorbidity are often characterized by a state of flux, in which self-management

priorities can change from day to day [1, 3]. The suffering from multimorbidity can be greater than the sum of its parts; it is an encounter with complexity because illness impacts both bodily and emotional health and brings social consequences [3, 17]. For these patients, the future is uncertain because chronic disease can take different courses: most typical in old age is prolonged gradual decline in physical function from an already low baseline. Otherwise, illness trajectories can be punctuated by episodes of acute deterioration and some recovery [21]. Declining physical capacity in older individuals often manifests itself in falls and fall-related injuries [22]. There is a risk that minor physical events can be fatal for patients when they occur in combination with declining reserves [21]. Because the actors' perceptions of the situation may differ, achieving patient participation can be particularly challenging in this patient group. For health professionals to enable patients to participate in the care-planning process, they need to take individual capabilities, preferences, and perceptions of illness into consideration [2, 18].

To facilitate integrated care, more knowledge is needed about what is happening in care-planning conversations and how to overcome interactional difficulties to understand patients' perspectives [1, 23, 24]. This study explores a care-planning intervention in Norwegian municipal health services, focusing on patient participation through two research questions:

What is the patients' role in care-planning meetings?

How do patients experience participating in care-planning meetings?

## Methods

### Design

This qualitative study is inspired by constructivism, which explores the realities people construct and the implications of those constructions for individuals' interactions with others [25]. To capture the interactions and experiences involved in patient participation, we combined direct observations [25] of ten care-planning meetings and individual interviews with the patients immediately after participation in the meeting. Observations are particularly suitable for exploring interactions [26] because they provide opportunities to describe the setting, activities, and actors in detail, thereby allowing a better understanding of the context [25]. Individual interviews provide insights into the patients' experiences of these meetings. The analysis aimed for concept development through a process called stepwise-deductive induction [26].

### The Norwegian context and the care-planning intervention

In Norway, services for older people are broadly accessible and primarily financed, organized, and delivered by

public entities in the municipalities [27]. This study includes health services in community hospitals, nursing homes, and patients' homes. The care-planning intervention was carried out as follows: After an individual patient experiencing an acute episode of disease was allocated health care services by the municipality, the patient was invited to participate in planning how these services could be delivered. Health professionals asked, 'What matters to you?' as a basis for a conversation about what was important to each individual patient [28, 29]. The patient and health professionals formulated a goal to work towards over the following weeks. Care planning with patients occurred either in conversations with one health professional or during interprofessional meetings. The intervention could be repeated in later care-planning meetings.

### Recruitment and sample

We purposively chose four municipalities that had implemented the intervention. Two municipalities were urban areas with 40,000 and 70,000 inhabitants, respectively, while two rural municipalities had 2000–3000 inhabitants. We observed meetings in clinical settings occurring independently of the present study. We aimed for a purposive sample of meetings in different kinds of wards involving patients in different stages of illness trajectories. Managers at the wards asked the eligible patients to participate, and the patients were approached face to face. The inclusion criteria were patients having multimorbidity and newly emerged needs for health and care services so that care planning was needed. The age of the patients was determined by the municipalities' routines; the intervention was applied primarily for patients over 80 years of age but could be used for younger patients in rehabilitation wards if they had complex needs. The exclusion criteria for the current study were cognitive impairment and short life expectancy. The number of patients who refused to participate in the study was not counted because we could not control whether the health professionals who recruited patients declined to invite certain patients. However, we did not aim for a representative sample.

### Data collection

From October 2018 to December 2019, the first author carried out direct observations of care-planning meetings and conducted patient interviews. During these observations, the researcher attempted to assume a neutral role and filled out an observation guide about the structure of the meetings and patient participation during the meetings (Additional file 1). The meetings lasted for 41 min on average. Observations were also carried out before and after the meetings, and informal talks with health professionals

provided additional information about the context. Field notes were written after each observation and interview.

The interviews with patients were carried out in patient's rooms or meeting rooms on the wards or in their homes. The semi-structured interview guide [30] focused on patients' experiences of participation in care-planning meetings (Additional file 1). Neither patients' relatives nor health professionals were present at the interviews, which lasted for 36 min on average. The length of each interview was adjusted to the energy level of the patient. One of the interviews was conducted by telephone. The interviews and meetings were audio-recorded and transcribed verbatim by the first author. The last meeting was not audio recorded, but thorough notes related to the observation guide and citations were written. After observation of the ten meetings, patterns were detected in how the meetings were organized and carried out across the different settings, and the material was considered substantial enough to convey information about the intervention.

### Analysis

Stepwise-deductive induction is based on grounded theory. In this process, the analysis begins inductively and subsequently draws on existing theory in concept development. We chose this method because it aims to elaborate new ideas from empirical data. Moreover, the analysis involved is more linear than in grounded theory [26]. The stages of the analysis are 1) empirical close coding, 2) grouping codes to subcategories, 3) merging subcategories with theory, and 4) concept development. The coding process is iterative between adjacent stages. Elements in the empirical data that trigger analytical ideas are recorded in memos [26].

The first author carried out the analysis in regular discussion with the co-authors. Firstly, she coded the transcripts by labeling small sections of text, resulting in 530 inductively based codes. The coding was more focused than that described by Tjora [26], as our codes were meant to convey meanings that could help to answer the research questions. The field notes were not coded but provided contextual understanding for the authors. Secondly, codes were sorted into groups based on the level of coherence in each group; see the example of coding in Table 1.

All authors discussed the code groups and how to interpret the emerging patterns, as well as discussing the different roles of participants.

### Inclusion of theory

Thirdly, code groups were linked to theory. In particular, game theory was deemed to be relevant because games can serve as a metaphor through which to understand

**Table 1** Example of codes

Empirical close codes	Code group
'Cannot let you know if I faint, it happens so fast'. Scared by the risks surrounding the symptoms. Wanted to live at home but did not manage to. Unsure how long things will continue to go well. I wish to await the decision about rehabilitation service at home. My symptoms determine the plans.	Patients' experience of uncertainty
But you just came here; you may recover quickly. Your symptoms are common in old age. 'We can predict that your situation will improve'. We test if the patient is ready to go home through a few days' home visit. We will do anything for you to be safe at home.	Health professionals' efforts to take control of uncertainty

patient participation [31, 32]. The more precise term for game theory is 'interactive decision theory' or 'theory of interdependent decision making' [33–35]. According to this theory, the encounter between patients and health professionals can be understood as a two-way interaction in which the outcome is affected by the actions and choices of each participant, leading to different types of games [32, 36, 37]. The roles of the players can be those of teammates, contenders, opponents, decision-makers, or subordinates [33, 38]. The interaction patterns in our data correspond to three kinds of games found in theory. The categories of these game types were developed by going back and forth between the empirical data and the theory.

During the following conceptualization, we chose to 'zoom in' [39] on the coding groups relating to uncertainty in decision-making. In game theory, 'uncertainty' means that the outcomes of decision-making do not depend solely on the actions of the players but rather are subject to the invisible hand of chance. This element of randomness can be depicted as resulting from the moves of an imaginary player: Nature [33]. We examined how the informants assessed uncertainty in care planning by looking for statements reflecting beliefs about whether and how one could plan care and the likelihood that these plans would come to fruition. Finally, we examined levels of patient participation. At a low level, patients sought or received information without participating in decision-making. At a medium level, the collaboration involved dialogue, but health professionals made the final decisions. A high level of participation involved shared decision-making based on patients' preferences, medical evidence, and clinical judgment [4, 23, 36, 40]. Additional file 2 more thoroughly describes the conceptual framework. The data were managed using NVivo [41] software.

## Results

Ten patients participated. Their mean age was 88 years. Eight of the patients had been hospitalized during the current disease episode. The main health problem that

had led to contact with health services was in each case intertwined with other diagnoses. All patients had functional decline, and none could walk without aids or help. Two of the patients had a salient mental diagnosis. Table 2 provides an overview of the study participants.

### The care-planning games of uncertainty

The objective of the care-planning intervention in this context was to agree on a rehabilitation goal that will facilitate the patient's discharge to his or her home. The care-planning meetings took place early in the recovery process, in most cases following a hospital admission and change in functional status. The meetings were mainly discussions to gain an overview of patients' medical symptoms and practical problems related to declining functional abilities.

In the context of game theory, the patterns of interaction between the actors in these meetings can be understood as games with four kinds of players. The first was the patients, who had unsolved, inconclusive disease symptoms and required ongoing medical treatment. They often played under difficult conditions, being in an uncertain and confusing situation. Moreover, the interviews indicated that the patients felt disoriented about which services they would receive and when. These were decisions in which they perceived themselves to have little influence. The patients attempted to be cooperative players. Health professionals, the second kind of players, often drove the meetings, which began with each health professional presenting an evaluation of the health status of the patient. Health professionals played on their home ground: they had an overview of the situation and knew the rules of the game and the routines prescribed by the intervention. They were also the ones who pushed the decision-making to a conclusion. The third kind of player was relatives. Because the intervention does not specify questions addressed directly to relatives, relatives were assigned the role of observers who provided information and helped the patients. Sometimes they also acted as advocates for the patients, taking on a more active role.

**Table 2** Characteristics of the ten care-planning meetings and the patients

Patient's gender, age	Patient's main health problem, number of diagnoses, and ward	Participants in the care-planning meeting
P#1 Female, 86 years	Fractured arm. > 2 diagnoses. Start of stay at rehabilitation/intermediate care unit, city municipality.	Patient and a nurse.
P#2 Female, 96 years	Chest pains and abdominal pain. > 4 diagnoses. Start of stay at rehabilitation/intermediate care unit, city municipality.	Patient and a nurse.
P#3 Female, 97 years	Fall, fractured neck of femur, with infection. > 5 diagnoses. End of stay at rehabilitation ward, city municipality.	Patient, case manager from office handling allocation of services, physiotherapist, nurse, home care nurse, and daughter. Three nursing students observed the meeting.
P#4 Female, 98 years	Several falls assumed to be caused by orthostatic hypotension. > 2 diagnoses. End of stay at rehabilitation ward, city municipality.	Patient, case manager from office handling allocation of services, nurse at the ward, home care nurse, daughter, and adult granddaughter.
P#5 Female, 62 years	Pneumonia. > 5 diseases. Middle of stay at intermediate care unit, city municipality.	Patient, husband, case manager from office handling allocation of services, and nurse from the ward. One nursing student observed the meeting.
P#6 Female, 91 years	Weakened by cumulative effect of multiple conditions. > 5 diagnoses. Middle of stay at rehabilitation ward, city municipality.	Patient, case manager from office handling allocation of services, home care nurse, and ward nurse. Daughter and two sons.
P#7 Male, 94 years	Functional decline and emerging needs for home care services. > 5 diagnoses. Meeting at patient's home before short-term stay at nursing home, rural municipality.	Patient, wife, and nurse in home care services.
P#8 Female, 96 years	Syncope. > 2 diagnoses. Meeting at patient's home, right after stay in intermediate unit, rural municipality.	Patient and nurse in home care services.
P#9 Female, 86 years	Hip surgery. > 5 diagnoses. Middle of stay at short-term ward, rural municipality.	The patient did not wish to participate in the meeting. Four daughters, head nurse at care home, physiotherapist, and nurse.
P#10 Male, 75 years	Fractured neck of femur. > 4 diagnoses. End of stay at short-time ward, rural municipality.	Patient, head nurse in home care services, physician, physiotherapist, mental health nurse, case manager, daughter, son, and nurse from home care services.

The fourth player in the game is the imaginary player called 'Nature', an objective force with the power to change the plans for service delivery when incidents such as disease, or improvements in health, occur by chance. Nature acts in unpredictable ways, leading to uncertainty. Although uncertainty is always present as a factor, the players assessed its importance differently, and these differences affected their planning of care. For example, if a patient had previously suffered a fall, the players considered whether to account for the possibility of further falls. The players' different approaches to care planning shaped their arrangements, roles, and interactions. In particular, varying perceptions of the level of uncertainty and its importance in the game among players, and consequently how their actions related to Nature, shaped three different types of game: the game of chance, the competitive game, and the coordination game. The different games represent interaction patterns observed in the care-planning meetings. Different games could be played out in the same meeting, depending on

the topic that were discussed. In the following, we describe the characteristics of each game.

#### *The game of chance*

In care-planning decisions that followed the pattern of the game of chance, patients seemed to perceive future events as uncontrollable and random. They felt out-matched by the opponent Nature, believing that the course of the disease and what happened within the health system would be dictated by chance. Their health professionals and relatives were relegated to the role of spectators on the sideline, in the sense that the outcome of care planning was understood to be determined more by Nature's actions than by the patients' own will or engagement in decision-making with other players. Consequently, when health professionals asked patients in this category what mattered to them, the patients were passive and expressed few preferences. They became receivers of information about the plans and goals that health professionals and relatives set for them.

In the interactions observed, several patients anticipated a deterioration of health, expressing fear of incomprehensible symptoms, pain, or severe illness. Many had already experienced sudden health deterioration in the form of falls or acute hospital stays:

Patient: I really hope the infection stays under control so that I can go through with this. This is the fifth time the operation has been scheduled. (meeting, P#5).

Moreover, patients felt unable to predict their level of physical strength or tiredness from day to day, meaning they did not know how active they could be in the recovery process. Patient 9, for example, suggested that her well-being was beyond her control:

Interviewer: So you were at the hospital not too long ago?

Patient: Hip surgery. And it went just fine. Now afterwards, it's been a big mess. I fell a few times.

Interviewer: Oh, you have, huh? I see.

Patient: It was all going so well when I got back, but then things just took a turn. I don't know what caused it. (interview, P#9).

This patient chose not to attend the care planning meeting. Other patients' feelings of uncertainty appeared when they agreed only doubtfully to health professionals' plans, making qualifying statements such as 'I hope.', 'we will see if.', 'I'll try', and 'if something does not occur'. Through the lens of game theory, these interactions appear as ones in which the role of Nature was understood to be strong, meaning that patients could not predict the outcomes of their available choices. Those patients who appeared to experience the greatest levels of uncertainty did not look forward or articulate any health-related goals:

Case manager: What do you think if you look ahead a bit, what is important to you in the situation you are in now?

Patient: Just that you all keep being good to me and, well, I don't feel so positively about me getting better. (meeting, P#6).

Patients' expressions of uncertainty, fear, or a sense of chaos were little explored or discussed by the health professionals, whose moves were, rather, to calm patients down and emphasize their own control of the situation:

Patient: It all just snowballs.

Nurse: And I think it's important for you and [spouse], now that you are juggling a lot of things at once what with your ear and your stomach and your back that you had looked at a few days ago, that you try to focus on only one thing at a time. And right now, it's the surgery. Have some fun this weekend.

Patient: Ok, ok.

Nurse: Come back on Monday. We have it under control. We will help you with what you need. And only focus on that. When that's done with...we'll take the next thing. If you think about everything it'll just create this chaos in your ...

Patient: I know, I know. But I have to say, I'm dreading that operation, because she said so many things that could go wrong if...but that was only a percentage, of course. Even paralysis.... (meeting, P#5).

Health professionals emphasized areas in which the patients' health was good and pointed out the activities the patient could manage in their daily life. They also offered security by placing safety alarms in the patients' homes in case of critical events or asking patients about what they needed to feel safe. However, in the language of game theory, the safety offered by health professionals was insufficient to defeat the player Nature. The patients were subordinated to Nature and consequently to other players as well because of their passivity in decision-making.

### ***The competitive game***

In care-planning decisions that followed the pattern of the competitive game, the players formed two sides: one side perceived Nature as a significant threat, emphasizing the high degree of uncertainty in the care trajectory and worrying about how to plan for the risk of deteriorating health. The opposing side was less preoccupied with Nature. The courses of action proposed by each side differed, and the two sides consequently disagreed about the patients' need for services.

Youngest son: Then I would like to take it a step further: if she isn't functioning well enough to come home—then what do you do?

Coordinator: Then we apply for a different living situation. Right? Like a different level of care. Yeah. But we're not there yet, no. (*light laughter*).



Youngest son: Right, no. But just to have asked that question in time.

Coordinator: Right. Well, we'll deal with it when it's ... (...).

Youngest son: Well, I still think it's relevant to ask that. She is nearly 92, after all. (meeting, P#6).

These competitive games ended with winners and losers in decision-making because one of the sides disagreed with the final decisions. The level of patient participation depended on which side of the game the patient was on.

How the players distributed themselves between the two sides varied. Often, relatives wanted more health services for the patient, either because they perceived a high level of risk in the patient continuing to live at home or because they were exhausted by helping. The health professionals aligned themselves against these preferences when they did not accord with the routines and resources available. Another division of players could occur if the patient did not align himself against Nature when the other players all did. For example, the relatives could form an alliance with health professionals to persuade the patient to receive more health services in order to manage everyday life or reduce the risk of adverse events. Even when the patients seemed unaware of or untroubled by that risk, they had minimal opportunity to influence the decisions.

Nurse: Is there something you have been thinking about that might be important to you that you can tell us, something you'd like to continue with or achieve?

Patient: It's a little difficult, that, right now.

Wife: I think it's important for you, I have to say, that I am there to help you. (...) I'm the one responsible. You wouldn't manage alone. (...).

Nurse: Have you given that any thought? (*short silence*) Is there something she does for you that we at home care services can help you with?

Patient: No, that would ... What might that be?

(*15 s silence*)

Nurse: You can't think of anything? (meeting, P#7).

In cases such as these, the negotiation between opposing sides overshadowed the focus on the patients' values and preferences in care planning.

### **The coordination game**

In care-planning decisions that followed the pattern of the coordination game, all players either aligned themselves as teammates against Nature or else did not ascribe much importance to the forces represented by Nature. Patients, health professionals, and relatives coordinated their care-planning strategies to accommodate uncertainty and risk, thereby arriving at a shared goal for care. When the players assessed the risk of health deterioration to be high, viewing Nature as a strong opponent, they planned to stay on the safe side and collaboratively discussed fears and contingencies. The dialogue also elicited how each of the players perceived risk.

Grandchild: ... We'll have to discuss it with the home care services, I think. Maybe get more frequent visits and ...

Daughter: But she is scared at home, you know.

Coordinator: It's all the hours when you aren't here, that's a lot of hours in a day.

Home care nurse: And the nights, especially.

Coordinator: A day center is an alternative, but that still won't cover all 24 h, you know. It's about finding a solution. Yes.

Grandchild: I'm sure there is. There is always a solution.

Coordinator: It's just that ...you feel unsafe being at home.

Patient: Yes, and I never know what might happen. (meeting, P#4).

This dialogue ended with agreement among the players that long-term care in a nursing home was the best solution. The patient repeated in the interview that she preferred this option.

In an opposite sort of scenario, the game could unfold as if Nature were not present; all players perceived the level of uncertainty to be low, and they assessed the situation as uncomplicated. This version of the game may have occurred because patients' diseases were less complex, as in the case of a woman with a broken arm.

Coordination games were characterized by the time taken to share perceptions of uncertainty and to talk about the available options for care. The players did not form factions through the decision-making process, and they agreed on goals. The patients themselves were

active and equivalent to other players in the decision-making.

**The concept of the game of uncertainty**

Table 3 sums up the characteristics of the different types of games that unfolded depending on how the players assessed uncertainty. We suggest that perceptions of uncertainty were associated with different patient roles and levels of patient participation. This observation forms the point of departure for our discussion.

**Discussion**

Goal-oriented care-planning interventions have been implemented to increase patient participation so that service delivery better aligns with patients’ values, preferences, and needs [8, 11, 12]. In some Norwegian municipalities, care planning is based on the question ‘What matters to you?’ [28, 29]. The present study explores the experience of participation for older patients with multimorbidity and the types of interactions involved. Decision-making interactions were shaped by different responses among players to the elements of uncertainty in the situation: the unknown course of the disease, unfamiliarity with the service delivery process, and the uncertain future self-management abilities of patients. Differences in how participants in the care-planning meetings assessed uncertainty, and thereby contended with the imaginary player Nature, led to the appearance in the care planning meetings of three different game patterns: the game of chance, the competitive game, and the coordination game. The level of patient participation was low in the game of chance, varied in the competitive game, and high in the coordination game. How each of the players accommodated uncertainty seemed to influence the patients’ opportunities and motivation to participate actively in care planning.

For the patients in the present study, uncertainty was central in the decision-making process and strongly affected the structure of the care-planning game. Previous studies investigating uncertainty in the context of patient participation have examined medical decision-making about prognosis and treatment options, mostly in patient–physician consultations [1, 42]. The influence of

uncertainty has also been studied within the context of life-limiting chronic disease and cancer [43, 44]. A review of how integrated services for older people living at home address patients’ safety shows that safety is protected by preventing (unnecessary) health decline, polypharmacy, and uncoordinated service delivery [45]. However, although health and social care providers in thirteen case studies of European care programs thought they had sufficiently addressed safety issues, older people often still felt insecure [46].

According to game theory, assessments of uncertainty involve a feeling of ignorance about the future, meaning that the player cannot assign meaningful probabilities to the outcome of the game [33]. Similar descriptions can be found in previous health research suggesting that uncertainty about illness can affect patients’ temporal focus for a period: some patients focus only on current events and ignore the future. What is more, ignorance about the future reduces patients’ engagement and desire for information [43]. This issue needs attention from health professionals involved in care planning because the literature identifies patients’ perceptions of control as an internal factor important for their self-management in cases of chronic disease [24, 47].

The different game structures we have identified illustrate some underlying dynamics governing the interactions involved in care planning [32]. Game theory offers the advantage, in the present study, of illuminating how the players’ roles as passive participants, opponents, or teammates influenced the levels of patient participation in the three different types of game we observed. The first type, the game of chance, has a structure in which one player awaits the moves of another, more powerful player, Nature [33]. In the meetings we observed, patients who felt overwhelmed by Nature’s potential influence on their situations received information passively from health professionals, resulting in a low level of participation. Charles et al. [36] point out that many patients faced with serious illness, uncertainty about the outcome, and time pressure to make treatment decisions can feel extreme psychological and/or physiological vulnerability, which may make it difficult for them to participate in decision-making, no matter how well

**Table 3** The concept of the game of uncertainty

	Game of chance	Competitive game	Collaborative game
<b>Uncertainty</b>	The patient assessed uncertainty to a greater degree than other players. Temporal focus: did not look forward.	The players assessed the level of uncertainty differently.	The patient’s understanding of uncertainty was shared with other players. Temporal focus: the future.
<b>Participants’ roles</b>	Patient fighting alone against Nature.	Two sides, in which one of the sides saw Nature as an opponent.	All players were teammates, either aligning against Nature or not feeling threatened by it.
<b>Level of patient participation</b>	Low: the patient received information, was less active. Health professionals set goals for care.	Varied: depended on which side of the game the patient took. Difficult to agree on goals for care.	Higher: the patient functioned as an equal player within the team. Easier to agree on goals for care.

informed they might be [36]. This situation may apply to older patients with multimorbidity, in which illness is an encounter with complexity, affecting several areas of life and with an unknown course [3, 17, 21]. Feeling out-matched by the imaginary player Nature may influence the possibility of patients participating in their care planning and their motivation to do so.

The competitive version of the game had the structure of a competition between sides. This result is in line with studies showing that mismatches in the way patients and health professionals interpret and frame a patient's health problems hamper patient participation [1]. One possible explanation for the occurrence of a competitive game is that this care-planning intervention focuses on self-management and health maintenance. In some cases, this focus excluded any dialogue about how the participants assessed age-related health deterioration and risks. The most typical illness trajectory in old age is prolonged gradual decline, often punctuated by episodes of acute deterioration and some recovery [21]. This raises questions about the feasibility of the intervention in the context of integrated care for older patients with multimorbidity. More work remains to be done on how to apply this intervention with this patient group to reach high-quality care through active participation.

Finally, coordination games have a structure in which the players coordinate their strategies [33]. This version of the game was the only one reaching the level of 'shared decision-making' [36, 40]; when uncertainty was high, all players related to it. Dialogue and an evaluation of options is an important component of shared decision-making [36, 43], and these elements allowed patients playing this game to participate despite the destabilizing presence of Nature. This dynamic was seen when some patients received support from health professionals through the segment of the meeting allotted to dialogue, which elicited differences in perceptions of uncertainty among the participants.

According to the ideals of integrated care, patients should be at the center of decisions about health service delivery, leading to greater self-management [2, 10]. This ideal may be difficult to achieve for some older patients with multimorbidity, as the acute phases of their diseases may be similar to those of patients with advanced illnesses in terms of how they deal with uncertainty during the course of the illness and in the future [43]. In the present study, the extent to which health professionals explored how patients assessed and handled uncertainty, thereby helping them to a better understanding of their situation, was low. For patients to become active participants—as the intervention requires—our study suggests that patients first need an overview of their own situation; it also illustrates the important role of health professionals in this process. Based on these arguments, the

present study suggests that patient participation may increase if patient uncertainty is attended to in care planning.

### Strengths and limitations

The method of direct observation is influenced by the researcher's perceptions and interpretations [25, 26]. Hence, the significance assigned in our analysis to uncertainty is one among multiple possible interpretations. It is known that in studies of patient participation researchers make attributions about the participants' internal decision-making processes based on what the researchers observe [36]; this could be a limitation of the analysis conducted here. However, the triangulation of observations and interviews contributes to the credibility of the findings [25].

In the recruitment process, health professionals could have excluded patients with whom they perceived collaboration to be difficult. In addition, the observer could have influenced the meetings [25] if her presence led participants to behave more agreeably. Our study sample is too small to determine how often uncertainty appears in decision-making with this category of patients or the extent to which it influences patient participation. Other patterns of interaction may exist in such meetings which we were unable to capture with a sample of this size. Our concept is thus modifiable; we cannot draw conclusions as to whether a relationship exists between uncertainty, roles, and patient participation. However, our results are transferable to similar contexts insofar as they illustrate how interactions between elderly patients with multimorbidity and health professionals can be interpreted as a game in which uncertainty plays a part.

### Implications

Interventions aimed at facilitating patient participation do not automatically obtain their goal [14]. Patients' individual beliefs and their perceptions of personal control influence decision-making and self-management [47]. To enable patients to participate, it may be beneficial to include a dialogue that elicits how uncertainty is assessed by the various participants in care-planning meetings. There are several specific ways in which this issue could be addressed in the intervention. First, questions could be included about whether and how patients perceive uncertainty within their situation. We found that health professionals used most of the time in the meetings to collect and share medical information. However, a different distribution of time in the meetings, with more time allocated to discussions of perceptions of uncertainty, might benefit some patients with complex needs. Second, decision-making and goal setting should be adapted to the patients' temporal focus, that is, whether their focus is on the present or future [43].

Health professionals and patients can agree on the time-frame (e.g., days or weeks) for the plans they make. Making this dialogue an explicit component of care-planning interventions may increase person-centeredness and promote the alignment of service delivery with patients' own goals. Keeping the game metaphor and the imaginary player Nature in mind may increase health professionals and patients' understanding of care-planning interactions.

Because the influence of uncertainty does not apply to all patients equally, future research on the prevalence of this phenomenon is warranted. According to constructivist inquiries, concepts that are developed are open to continuous reconstruction because input from others leads to new or added meanings [48]. Further studies could refine the concept of uncertainty in care planning.

## Conclusions

The present study explores the experience of patient participation for older patients with multimorbidity in care-planning meetings within municipal health services. In the interactions observed, the actors' assessments of uncertainty were salient in decision-making, and three patterns emerged, which we describe here, drawing on game theory, as three versions of the interaction 'game': a game of chance, a competitive game, and a coordination game. These interactions help us understand why some patients participate less in care planning than others. We conclude that care-planning interventions for older patients with multimorbidity should mandate that health professionals elicit and discuss uncertainty to achieve goal-oriented care based on patients' preferences, values, and needs. Further research could explore the role of uncertainty in these meetings and how health professionals and patients can accommodate it in care planning.

## Supplementary Information

The online version contains supplementary material available at <https://doi.org/10.1186/s12877-021-02184-z>.

**Additional file 1.** Observation and interview guides.

**Additional file 2.** The emerging conceptual framework - Patient participation in the care-planning game

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## Authors' contributions

All authors designed the study. JDO collected the data. JDO conducted most of the analysis, in regularly discussions with MS, RK and MKR. JDO wrote the draft, and MS, RK and MKRS contributed to manuscript revisions. All authors approved the final manuscript.

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## Availability of data and materials

The data generated and analysed in the current study are not publicly available due to Norwegian privacy legislation and the form signed by the participants about the study's privacy.

## Declarations

### Ethics approval and consent to participate

The study participants' rights, dignity and privacy were ensured according to the Declaration of Helsinki. The participants received oral and written information about the study. Written informed consent was obtained from all the participants. Participation was voluntary, and the participants could withdraw at any time without explanation. The participants' dignity was attended to while the methods were performed. In observation of one of the interprofessional meetings, two of the health professionals did not want the meeting to be audio recorded and this was respected without asking them to justify why. The Regional Committee for Medical and Health Research Ethics Midt-Norge waived the need for approval of the study (ref. 2018/852/REK midt). The Norwegian Centre for Research Data approved the study (project number 60524).

### Consent for publication

Not applicable.

### Competing interests

The authors declare that they have no competing interests.

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## Appendices

Appendix 1: Approval from Norwegian Centre for Research Data

Appendix 2: Letter from The Regional Committee for Medical and Health Research Ethics

Appendix 3: Information about the study given to health professionals

Appendix 4: Information about the study given to patients

Information about the study given to patients' relatives

Appendix 5: Interview guide for focus groups with health professionals

Appendix 6: Observation guide for care-planning meetings

Appendix 7: Interview guide for individual interviews with patients





Jannike Oksavik

6025 ÅLESUND

Vår dato: 04.06.2018

Vår ref: 60524 / 3 / PEG

Deres dato:

Deres ref:

## Tilråding fra NSD Personvernombudet for forskning § 7-27

Personvernombudet for forskning viser til meldeskjema mottatt 26.04.2018 for prosjektet:

60524	<i>Brukermedvirkning i helhetlige pasientforløp for multisyke eldre</i>
<i>Behandlingsansvarlig</i>	<i>NTNU, ved institusjonens øverste leder</i>
<i>Daglig ansvarlig</i>	<i>Jannike Oksavik</i>

### Vurdering

Etter gjennomgang av opplysningene i meldeskjemaet og øvrig dokumentasjon finner vi at prosjektet er unntatt konsesjonsplikt og at personopplysningene som blir samlet inn i dette prosjektet er regulert av § 7-27 i personopplysningsforskriften. På den neste siden er vår vurdering av prosjektopplegget slik det er meldt til oss. Du kan nå gå i gang med å behandle personopplysninger.

### Vilkår for vår anbefaling

Vår anbefaling forutsetter at du gjennomfører prosjektet i tråd med:

- opplysningene gitt i meldeskjemaet og øvrig dokumentasjon
- vår prosjektvurdering, se side 2
- eventuell korrespondanse med oss

### Meld fra hvis du gjør vesentlige endringer i prosjektet

Dersom prosjektet endrer seg, kan det være nødvendig å sende inn endringsmelding. På våre nettsider finner du svar på hvilke [endringer](#) du må melde, samt endringskjema.

### Opplysninger om prosjektet blir lagt ut på våre nettsider og i Meldingsarkivet

Vi har lagt ut opplysninger om prosjektet på nettsidene våre. Alle våre institusjoner har også tilgang til egne prosjekter i [Meldingsarkivet](#).

### Vi tar kontakt om status for behandling av personopplysninger ved prosjektslutt

Ved prosjektslutt 30.06.2019 vil vi ta kontakt for å avklare status for behandlingen av personopplysninger.

Se våre nettsider eller ta kontakt dersom du har spørsmål. Vi ønsker lykke til med prosjektet!

*Dokumentet er elektronisk produsert og godkjent ved NSDs rutiner for elektronisk godkjenning.*

Vennlig hilsen

Marianne Høgetveit Myhren

Pernille Ekornrud Grøndal

Kontaktperson: Pernille Ekornrud Grøndal tlf: 55 58 36 41 / [pernille.grondal@nsd.no](mailto:pernille.grondal@nsd.no)

Vedlegg: Prosjektvurdering



### UTVALG OG REKRUTTERING

Utvalget består av helsepersonell og eldre pasienter over 80 år som etter sykehusopphold skal motta hjelp fra kommunehelsetjenesten. Den delen av utvalget som er pasienter vil være samtykkekompetente. Rekruttering skjer via helsepersonell i kommunen. Pasientene blir ikke rekruttert av helsepersonell som de har daglig kontakt med, men av helsepersonell ansatt som saksebehandlere e.l.

### FORMÅL

Formålet med prosjektet er for det første å innhente kunnskap om brukeres erfaringer med å få medvirke i planleggingen av de tjenester de selv skal motta fra primærhelsetjenesten, etter at de er utskrevet fra sykehus. For det andre skal det undersøkes hvilke erfaringer helsepersonell har med at brukere medvirker i planlegging av tjenestetilbudet, gjennom de arbeidsrutiner som benyttes for å involvere brukerne. For det tredje skal det undersøkes hvordan brukere medvirker i tverrfaglige møter mellom helsepersonell og brukere.

### INFORMASJON OG SAMTYKKE

Du har opplyst i meldeskjema at utvalget vil motta skriftlig og muntlig informasjon om prosjektet, og samtykke skriftlig til å delta. Vår vurdering er at informasjonsskrivene til utvalget er godt utformet.

Vi bemerker at personvernombudet har foretatt en vurdering på bakgrunn av dagens lovverk. I løpet av august 2018 vil imidlertid nye personvernregler gjelde. Blant annet stilles det nye krav til informasjon og samtykke, og behandlingsansvarlig institusjon må løpende vurdere om informasjonen som er gitt er tilstrekkelig etter det nye regelverket. For mer informasjon om det nye regelverket, og en veileder om samtykke, viser vi til Datatilsynets hjemmesider: <https://www.datatilsynet.no/samfunnsomrader/overordnet-om-rettigheter-og-plikter/samtykke/>

### SENSITIVE PERSONOPPLYSNINGER

Det fremgår av meldeskjema at du vil behandle sensitive opplysninger om helseforhold.

### INFORMASJONSSIKKERHET

Personvernombudet forutsetter at du behandler alle data i tråd med NTNU sine retningslinjer for datahåndtering og informasjonssikkerhet. Vi legger til grunn at bruk av mobil lagringsenhet (minnepinne) er i samsvar med institusjonens retningslinjer. Vi forstår at den mobile lagringsenheten er kryptert, og at den skal oppbevares i låsbart skap. Personvernombudet anser dette som et godt tiltak for å redusere risiko for at sensitive opplysninger kommer på avveie.

### PROSJEKTSLUTT OG ANONYMISERING

Prosjektslutt er oppgitt til 30.06.2019. Det fremgår av meldeskjema/informasjonsskriv at du vil anonymisere datamaterialet ved prosjektslutt. Anonymisering innebærer vanligvis å:

- slette direkte identifiserbare opplysninger som navn, fødselsnummer, koblingsnøkkel

- slette eller omskrive/gruppere indirekte identifiserbare opplysninger som bosted/arbeidssted, alder, kjønn
- slette lydopptak

For en utdypende beskrivelse av anonymisering av personopplysninger, se Datatilsynets veileder:

<https://www.datatilsynet.no/globalassets/global/regelverk-skjema/veiledere/anonymisering-veileder-041115.pdf>

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<b>Region:</b> REK midt	<b>Saksbehandler:</b> Marit Hovdal Moan	<b>Telefon:</b> 73597504	<b>Vår dato:</b> 19.04.2018	<b>Vår referanse:</b> 2018/852/REK midt
			<b>Deres dato:</b> 18.04.2018	<b>Deres referanse:</b>

Vår referanse må oppgis ved alle henvendelser

Jannike Dyb Oksavik  
NTNU

### **2018/852 Brukermedvirkning i helhetlige pasientforløp for multisyke eldre**

Vi viser til innsendt fremleggingsvurderingsskjema datert 18.04.2018. Henvendelsen har blitt vurdert av sekretariat.

#### **Komiteens prosjekttale**

Komiteen oppfatter prosjektet som en studie designet for å undersøke hvordan brukermedvirkning blir gjennomført og erfart i helhetlige pasientforløp for multisyke personer som er 80 år og eldre, nærmere bestemt om pasienten opplever å ha muligheten til å medvirke på hvilke tjenester han/hun mottar, dvs om pasienten fikk hjelp til det som var viktig for ham/henne. I tillegg skal man undersøke helsepersonells erfaringer med at pasienter får medvirke, gjennom arbeidsrutinen "Hva er viktig for deg?-samtalen". Samtykke planlegges innhentet.

#### **Vurdering**

Komiteen mener at prosjektet framstår som forskning, men ikke som medisinsk eller helsefaglig forskning; det vil si forskning med mål om å fremskaffe ny kunnskap om sykdom og helse. Prosjektet omfattes derfor ikke av helseforskningslovens saklige virkeområde, og kan gjennomføres uten nærmere etisk vurdering av REK. Vi minner imidlertid om at dersom det skal registreres personopplysninger, må prosjektet meldes til Norsk senter for forskningsdata (NSD).

#### **Merknad**

Vi minner om at vurderingen er gjort med bakgrunn i de innsendte dokumenter og kun er å betrakte som veiledende, jf. forvaltningsloven § 11. Dersom du ønsker at det skal fattes et formelt enkeltvedtak etter forvaltningsloven, må du sende inn en full prosjektsøknad til REK. En prosjektsøknad blir komitébehandlet iht. oppsatte frister. Dersom det gjøres endringer i prosjektet, kan dette ha betydning for REKs vurdering. Det må da sendes inn ny søknad/framleggingsvurdering.

Med vennlig hilsen  
Hilde Eikemo  
sekretariatsleder, REK midt

Marit Hovdal Moan  
seniorrådgiver

## Forespørsel om deltakelse i forskningsprosjektet

### «Brukermedvirkning i helhetlige pasientforløp for eldre personer med multisykdom»

#### **Bakgrunn og formål**

Mange kommuner arbeider med å endre rutiner i pasientforløp for eldre personer med multisykdom, det vil si brukere som har to eller flere kroniske sykdommer. Din kommune ble spurt om å delta fordi kommunen deltok i det nasjonale læringsnettverket «Gode pasientforløp for eldre og kronisk syke» og har innført det å spørre brukere «Hva er viktig for deg?» i pasientforløpet. Formålet med dette prosjektet er å undersøke helsepersonell sine erfaringer med å spørre brukere «Hva er viktig for deg?». Helsepersonell i fire kommuner blir intervjuet. Formålet er ikke å sammenligne kommuner, men å innhente kunnskap om helsepersonellerfaringer generelt.

Dette er en del av et doktorgradsprosjekt ved institutt for helsevitenskap ved NTNU.

#### **Hva innebærer deltakelse i studien?**

Du deltar i et gruppeintervju med annet helsepersonell. Intervjuet vil ta 1,5 time. Spørsmålene vil omhandle deres erfaringer med å spørre brukere over 80 år som har vært innlagt i sykehus «Hva er viktig for deg?», når brukerne skal motta helsetjenester i kommunen. Intervjuet blir tatt opp på en lydfil.

#### **Hva skjer med informasjonen om deg?**

Alle personopplysninger vil bli behandlet konfidensielt. Det er kun doktorgradsstudent og veiledere ved NTNU som vil ha tilgang til personopplysninger. Navneliste oppbevares i låst skap på NTNU og lydfilen lagres elektronisk på NTNU sitt område. Ved prosjektslutt blir alle direkte identifiserbare opplysninger som navn og lydopptak slettet, og indirekte identifiserbare opplysninger blir omskrevet. Doktorgradsprosjektet som helhet skal etter planen avsluttes i desember 2020. Ingen enkeltpersoner vil kunne gjenkjennes i publikasjon av studiens funn.

#### **Frivillig deltakelse**

Det er frivillig å delta i studien, og du kan når som helst trekke deg fra studien uten å oppgi noen grunn. Studien er godkjent av Personvernombudet for forskning, NSD - Norsk senter for forskningsdata AS. Prosjektnummer 60524.

Dersom du har spørsmål, ta kontakt med doktorgradsstudent Jannike Oksavik, telefon 996 290 77 eller 701 613 38, epost: [jannike.d.oksavik@ntnu.no](mailto:jannike.d.oksavik@ntnu.no) Du kan også kontakte prosjektleder og førsteamanuensis Ralf Kirchhoff, telefon 701 61 478, epost: [rk@ntnu.no](mailto:rk@ntnu.no)

Kommunen kan bidra med kunnskap som er viktig for videreutvikling av pasientforløp for eldre personer med multisykdom.

Vennlig hilsen Jannike Oksavik

## Forespørsel om deltakelse i forskningsprosjektet

### «Brukermedvirkning i helhetlige pasientforløp for eldre personer med multisykdom»

#### **Bakgrunn og formål**

Formålet med dette prosjektet er å undersøke hvordan helsepersonell gjennomfører å spørre brukere «Hva er viktig for deg?». Dette gjelder brukere over 80 år som nettopp er utskrevet fra sykehus og mottar tjenester i kommunen. Din kommune deltar fordi kommunen har deltatt i det nasjonale læringsnettverket «Gode pasientforløp for eldre og kronisk syke» og kommet langt i innføringen av arbeidsrutiner i pasientforløpet. Studien gjennomføres i fire kommuner.

Dette er et doktorgradsprosjekt ved institutt for helsevitenskap ved NTNU.

#### **Hva innebærer deltakelse i studien?**

Deltakelse i studien innebærer at undertegnede er tilstede under en samtale/møte dere har med bruker angående hva som er viktig for ham/henne. Det blir tatt lydopptak og notater av det som skjer i samtalen/møtet.

#### **Hva skjer med informasjonen om deg?**

Alle personopplysninger vil bli behandlet konfidensielt. Signert samtykkeskjema oppbevares i låst skap på kontor på NTNU. Lydopptak lagres på NTNU sitt elektroniske område. Det er kun doktorgradsstudent og tre veiledere ved NTNU som vil ha tilgang til disse personopplysningene. Prosjektet skal etter planen avsluttes i desember 2020. Personopplysninger og lydopptak slettes ved prosjektslutt. Ingen enkeltpersoner vil kunne gjenkjennes i publikasjon av studiens funn.

#### **Frivillig deltakelse**

Det er frivillig å delta i studien, og du kan når som helst trekke deg uten å oppgi noen grunn. Studien er godkjent av Personvernombudet for forskning, NSD - Norsk senter for forskningsdata AS. Prosjektnummer 60524.

Dersom du har spørsmål kan du ta kontakt med doktorgradsstudent Jannike Oksavik. Telefon 99 62 90 77 eller 701 613 38, e-mail: [jannike.d.oksavik@ntnu.no](mailto:jannike.d.oksavik@ntnu.no). Postadresse: Jannike Oksavik, Institutt for helsevitenskap, NTNU Ålesund, Postboks 1517, 6025 Ålesund. Du kan også kontakte prosjektleder og førsteamanuensis Ralf Kirchhoff, telefon 701 61 478, e-mail: [rk@ntnu.no](mailto:rk@ntnu.no). Postadresse: Ralf Kirchhoff, Institutt for helsevitenskap, NTNU Ålesund, Postboks 1517, 6025 Ålesund.

# Samtykke til deltakelse i studien

Jeg har mottatt informasjon om studien, og er villig til å delta

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(Signert av prosjektdeltaker, dato)



## Appendix 4: Information about the study given to patients



### FORESPØRSEL OM DELTAKELSE I FORSKNINGSPROSJEKTET

## BRUKERMEDVIRKNING I HELHETLIGE PASIENTFORLØP FOR ELDRE PERSONER MED MULTISYKDOM

Mange kommuner har nye rutiner for oppfølging av brukere i kommunehelsetjenesten. Hensikten med dette doktorgradsprosjektet er å undersøke hvordan personer over 80 år opplever å bli spurt hva som er viktig for dem, når hjelpen de skal få etter sykehusopphold planlegges. Du blir spurt om å delta, fordi du nettopp har vært innlagt i sykehus.

Institutt for helsevitenskap ved NTNU i Ålesund er ansvarlig for og gjennomfører forskningsprosjektet.

### HVA INNEBÆRER PROSJEKTET?

Deltakelse i forskningsprosjektet innebærer to ting: For det første at du blir intervjuet og for det andre at doktorgradsstudenten er tilstede i et møte du har med helsepersonell.

Intervjuet vil ta inntil en time. Vi ønsker å høre dine erfaringer med at helsepersonell spør hva som er viktig for deg, når hjelpen du skal få fremover planlegges. Intervjuet vil bli tatt opp på en lydfil. Noen av deltakerne i prosjektet kan bli spurt om de ønsker å delta i et intervju til etter en måned.

I tillegg ønsker doktorgradsstudenten å være tilstede i et møte helsepersonell skal ha med deg, der det blir planlagt hvilken hjelp du skal få fremover. Møtet blir tatt opp på en lydfil og det blir tatt notater av hva som skjer i møtet.

I prosjektet vil vi ikke innhente andre opplysninger om deg enn det som kommer frem i intervju og i møtet.

### MULIGE FORDELER OG ULEMPER

Å delta i prosjektet vil ikke innebære risiko for deg. Du vil få samme behandling av helsepersonell uansett om du deltar prosjektet eller ikke. Ulemper er at noen kan oppleve det slitsomt å bli intervjuet eller at det er rart å at en forsker er tilstede i møtet en har med helsepersonell. Fordelen at du kan fortelle om dine erfaringer med helsetjenesten.

## FRIVILLIG DELTAKELSE OG MULIGHET FOR Å TREKKE DITT SAMTYKKE

Det er frivillig å delta i prosjektet. Dersom du ønsker å delta, signerer du på siste side. Du kan når som helst og uten å oppgi noen grunn trekke deg fra prosjektet. Da slettes innsamlede opplysninger om deg, med mindre opplysningene allerede er anonymisert og har inngått i analyser eller er brukt i vitenskapelige publikasjoner. Dette vil ikke få konsekvenser for din behandling i helsetjenesten om du trekker deg.

Dersom du senere ønsker å trekke deg eller har spørsmål til prosjektet, kan du kontakte doktorgradsstudent Jannike Oksavik, telefon 701 613 38, [jannike.d.oksavik@ntnu.no](mailto:jannike.d.oksavik@ntnu.no). Postadresse: Jannike Oksavik, Institutt for helsevitenskap, NTNU Ålesund, Postboks 1517, 6025 Ålesund. Du kan også kontakte prosjektleder og førsteamanuensis Ralf Kirchhoff, telefon 701 61 478, email: [rk@ntnu.no](mailto:rk@ntnu.no). Postadresse: Ralf Kirchhoff, Institutt for helsevitenskap, NTNU Ålesund, Postboks 1517, 6025 Ålesund.

## HVA SKJER MED INFORMASJONEN OM DEG?

Informasjonen som registreres om deg skal kun brukes slik som beskrevet i hensikten med prosjektet. Alle opplysninger vil bli behandlet uten navn og fødselsnummer eller andre direkte gjenkjenner opplysninger. Det betyr at ingen andre enn prosjektgruppen på NTNU får vite hva akkurat du har sagt eller opplysninger fra møtet mellom deg og helsepersonell.

Prosjektleder har ansvar for den daglige driften av forskningsprosjektet og at opplysninger om deg blir behandlet på en sikker måte. Navn på deltakere i studien låses inne i et skap på NTNU. Lydfilene lagres elektronisk på NTNU sitt område. Informasjon om deg vil bli anonymisert, senest ved prosjektslutt i desember 2020. Da blir lydfilene slettet. Det vil ikke være mulig å gjenkjenne personer i skriftlige eller muntlige presentasjoner av prosjektet.

## GODKJENNING

Prosjektet er godkjent av Norsk Senter for Forskningsdata (NSD), prosjekt nr. 60524.

SAMTYKKE TIL DELTAKELSE I PROSJEKTET

JEG ER VILLIG TIL Å DELTA I PROSJEKTET

-----  
Sted og dato

-----  
Deltakers signatur

-----  
Deltakers navn med trykte bokstaver

-----  
Jeg bekrefter å ha gitt informasjon om prosjektet.

-----  
Sted og dato

-----  
Signatur

Forespørsel til pårørende om deltakelse i forskningsprosjektet

## Brukermedvirkning i helhetlige pasientforløp for eldre personer med multisykdom

Mange kommuner har nye rutiner for oppfølging av brukere i kommunehelsetjenesten. Hensikten med dette doktorgradsprosjektet er å undersøke hvordan personer over 80 år blir spurt hva som er viktig for dem, når hjelpen de skal få etter sykehusopphold planlegges. Institutt for helsevitenskap ved NTNU i Ålesund er ansvarlig for og gjennomfører prosjektet.

### Hva innebærer deltakelse i prosjektet?

Undertegnede ønsker å være tilstede i et møte den du er pårørende til, har med helsepersonell. Hensikten er å undersøke hvordan helsepersonell spør brukere hva som er viktig for dem når det planlegges hvilken hjelp de skal få fremover. Pårørende er ikke fokus for dette prosjektet, men møtet blir tatt opp på en lydfil og det blir tatt noen notater. Dette kan innebære at opplysninger om deg som kommer frem i møtet også blir lagret. Å delta i prosjektet vil ikke innebære risiko for deg. Den du er pårørende til vil få lik behandling av helsepersonell uansett om du tillater at undertegnede er til stede i møtet eller ikke. Ulemper med å delta er at enkelte opplever det som rart å bli observert. Fordeler at en kan bidra til forskning på tjenestetilbudet.

### Frivillig deltakelse og mulighet for å trekke sitt samtykke

Det er frivillig å delta og du kan når som helst og uten å oppgi noen grunn trekke deg fra prosjektet. Da blir det du har sagt i møtet slettet, med mindre opplysningene allerede er anonymisert og har inngått i analyser eller er brukt i vitenskapelige publikasjoner.

Dersom du senere ønsker å trekke deg eller har spørsmål til prosjektet, kan du kontakte: Jannike Oksavik, telefon 701 613 38, email: [jannike.d.oksavik@ntnu.no](mailto:jannike.d.oksavik@ntnu.no). Postadresse: Jannike Oksavik, Institutt for helsevitenskap, NTNU Ålesund, Postboks 1517, 6025 Ålesund. Prosjektleder er førsteamanuensis Ralf Kirchhoff, telefon 701 61 478, email: [rk@ntnu.no](mailto:rk@ntnu.no).

### Hva skjer med informasjonen om deg?

Informasjonen om deg skal kun brukes slik som beskrevet i hensikten med studien. Alle opplysninger vil bli behandlet uten navn eller andre personidentifiserbare opplysninger. Det betyr at ingen andre enn prosjektgruppen på NTNU får vite hva du har sagt i møtet med helsepersonell. Prosjektleder har ansvar for den daglige driften av forskningsprosjektet og at opplysninger om deg blir behandlet på en sikker måte. Navneliste over deltakere i studien vil oppbevares innelåst i et skap på NTNU. Lydfilen lagres elektronisk på NTNU sitt område. Informasjon om deg vil bli anonymisert og lydfilen slettes ved prosjektslutt innen utgangen av

## Appendix 4: Information about the study given to patients' relatives

2019. Det vil ikke være mulig å gjenkjenne personer i muntlige eller skriftlige presentasjoner av prosjektet.

Prosjektet er godkjent av Norsk Senter for Forskningsdata (NSD), prosjekt nr. 60524.

Vennlig hilsen Jannike Oksavik

### Samtykke til deltakelse i prosjektet

Jeg samtykker i at det blir gjort lydopptak av møtet mellom meg, helsepersonell og den jeg er pårørende til.

---

Sted og dato

Deltakers signatur

---

## Appendix 5: Interview guide for focus groups with health professionals

### **Interview guide**

Can you describe what you do when you ask patients “What matters to you?”

Could you describe situations in which you asked, “What matters to you?” and the patients’ answer had implications for the help you gave?

Could you describe situations in which you asked, “What matters to you?” and the patients’ answer had minor implications for the help you gave?

Do the patients participate differently than before you implemented the “What matters to you?” procedure?

### **Theoretical sampling questions in the latest interviews**

What should one do when patients do not envisage any goals?

Which criteria do you consider when you say that a patient’s goal is realistic?

Do the relatives also express what matters to the patient?

## Appendix 6: Observation guide for care-planning meetings

This observation guide was filled out during and right after the meetings. The analysis of the meetings was however mostly based on the transcripts of audio recorded meetings, which allowed us to examine their normative justifications for patient participation according to the institutional logics.

<b>THE MEETING</b>		<b>RESEARCHER'S INTERPRETATION</b>
Time.	Time. Duration of the meeting.	
Description of the place.	Where, how the place looked, what happened in the context.	
Participants.	Number of persons, their roles. Patient:  Health professionals:  Relatives:	
Leader of the meeting		
Structure of the meeting	How they carried out the meeting.	
Agenda	The agenda for the meeting  - According to written documents/tools - According to what health professionals and/or patients said during the meeting	
Division of tasks.		
Did health professionals use tools or checklists?	Description of the tools and how they were used during the meeting.	
<b>Interactions</b>		
Did participants know each other?		
Atmosphere		
Formal/informal conversation	Areas of patients life and health they focused on.	
Communication	Professional terminology used?	

	Interruptions? Room for asking questions? Nonverbal communication	
<b>“What matters to you?”</b>	Who asked the question? What happened?	
What health professionals did to let patient participate.		
What the patient did to participate.		
Were there signs of less patient participation?		
Assessment of how the researcher influenced the situation.	<i>The researcher in most of the meetings asked participants about their experience of being observed.</i>	
Aspects which seem unclear, to be further examined (e.g. ask health professionals or patients after the meeting)		
Emerging aspects in the meeting?		



## Appendix 7: Interview guide for individual interviews with patients

Can you please tell me a little bit about your previous experiences with the health services? Can you tell me about what happened when you got ill this time?

What matters to you regarding the services you are going to receive from now on? (Explore what kind of goals the patient has)

I was present at the meeting, but I would like to hear how you experienced the meeting?

What was the aim of the meeting?

Did you get to know ahead of the meeting what the purpose of the meeting was? Have you received information about which services there are for older people in the municipality? Is the information given by health professionals and their choice of words understandable?

Who in the meeting decided what you are going to receive help for? Why?

Were you allowed to say what matters to you? Do health professionals include your wishes in decisions about service delivery?

Do you participate in making decisions in your own care pathway? Do you wish to participate?

Was there anything else you wished to talk about in the meeting that you did not discuss?

Follow-up questions about what I observed in the meeting (e.g., asking for their interpretations of what happened and why).

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