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Faculty of Health Sciences
Department of Community Medicine

Continuity of care for patients with long-term complex needs – implications for clinical hospital practice

A qualitative study

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Audhild Høyem

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Audhild Høyem

Department of Community Medicine
Faculty of Health Sciences
UIT The Arctic University of Norway

Department of Integrated Care
Centre for Quality and Development
University Hospital of North Norway

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Abbreviations

CP	Contact physician
CR	Coordination Reform
CU	Coordinating Unit
EHR	Electronic health record
GP	General practitioner
ICP	Individual care plan
iPP	Individual patient pathway
NICE	National Institute for Health and Care Excellence
PCC	Patient care coordinator
PC-IC	Person-centred integrated care
PVO	Data Protection Official for Research
REK	Regional Committees for Medical and Health Research Ethics
TO	The Troms-Ofoten study: “Mapping patient pathways in the Troms-Ofoten region”
WHO	World Health Organization
WPR	What is the problem represented to be? Analytical approach (Bacchi, 2009)

List of papers

Paper I

Høyem, A., Gammon, D., Berntsen, G. R., & Steinsbekk, A. (2018):

Policies Make Coherent Care Pathways a Personal Responsibility for Clinicians: A Discourse Analysis of Policy Documents about Coordinators in Hospitals.

International Journal of Integrated Care 18(3). doi:10.5334/ijic.3617.

Paper II

Høyem, A., Gammon, D., Berntsen, G., & Steinsbekk, A. (2018):

Keeping one step ahead: A qualitative study among Norwegian health-care providers in hospitals involved in care coordination for patients with complex needs.

International Journal of Care Coordination 21(1-2): 15-25. doi:10.1177/2053434518764643

Paper III

Berntsen, G., Høyem, A., Lettrem, I., Ruland, C., Rumpfeld, M., & Gammon, D (2018).

A person-centred integrated care quality framework, based on a qualitative study of patients' evaluation of care in light of chronic care ideals.

BMC Health Services Research 18(1). doi:10.1186/s12913-018-3246-z

Abstract

Background

Continuous specialization of professional competence, treatment and service provision has led to great successes. However, it has also resulted in increased complexity in the organization of healthcare, which in turn has led to fragmentation of services. Various measures have been introduced to overcome this fragmentation and to ensure continuity of care for the growing group of patients with chronic conditions or multimorbidity needing care from several providers and services. Despite new policy initiatives and ongoing research, there is still a lack of knowledge to support development, implementation, and evaluation of continuity of care-solutions for persons with diverse and complex needs in hospitals and across health services.

Aim

The overarching aim of this thesis was therefore to investigate implications for hospitals practices related to realizing continuity of care for patients with complex or long-term needs, at the intersection between policy, practice, and patient experiences. This was operationalized into three research questions covering Norwegian policy on coordinator roles in hospitals (Study I), experiences of health-care providers in hospitals who take on coordination responsibility (Study II), and experiences of person-centred integrated care for persons with multimorbidity (Study III).

Methods

Three different qualitative studies were undertaken to answer these questions; a discourse analysis of policy documents (Study I), an interview study with healthcare professionals (Study II), and an evaluative review of patients' pathway experiences as they were documented in patients' health records and reflected on by patients in individual interviews (Study III).

Results

In study I, it was found that the Norwegian policy documents framed the challenges, lack of coherent care pathways and lack of stable and responsible professionals for patients with complex needs, as a responsibility issue. The prescribed solution is extended personal responsibility for clinicians in the role of individual patient coordinators. The coordinators'

duties are described in terms of ideals for continuity of care. How to realize this role in heterogeneous hospital contexts is scarcely addressed.

In study II, experienced practitioners told how they ‘kept one step ahead’ and negotiated solutions in the local contexts to establish continuity of care for the patients they considered needed it the most. They developed personal and context-sensitive coordinator roles and adjusted their ambitions to what they considered doable within their personal authority and accessible resources.

In study III, it was found that patients evaluated their individual pathway experiences in relation to their long-term goals. They evaluated most care events as good. However, when their experiences were evaluated in relation to a process framework developed around goal-oriented person-centred integrated care, gaps in transfers, lack of a holistic approach, and lack of a pathway perspective from the providers became apparent. These gaps are invisible in event-based quality-of-care frameworks.

Conclusion

The Norwegian policies on coordinator roles in hospitals highlight ideals that resonate well with what patients want in terms of continuity of care. However, both patients with complex needs and healthcare providers with coordination responsibility in hospitals experienced substantial challenges related to the realization of these ideals.

Due to the variation in needs and goals of patients in need of continuity of care support, and the context-sensitivity of coordination practices, it is suggested that solutions for establishing continuity of care must be tailored to accommodate the unique combination of individual needs and the accessible coordination resources in the relevant care context. An approach for how to identify these needs and resources is put forward.

In order to facilitate sustainable solutions ensuring continuity of care for patients with complex needs, it is suggested to implement pathway infrastructures with some structural requirements, which still allow for individual variation. Recommended elements are a flow chart showing ideal pathway phases, mandatory documenting and reporting on designated points, systems for patient feedback during the process, and dedicated pathway coordinators.

Sammendrag

Bakgrunn

Spesialiseringen innen medisinsk behandling har ført til stadig mer spesialiserte enheter, en oppsplitting av helsetjenestene. Samtidig har spesialisthelsetjenesten plikt til å gi den enkelte pasient et helhetlig og koordinert tjenestetilbud. Det har vært introdusert ulike tiltak for den stadig økende gruppen av pasienter med sammensatte tilstander og behov for kontakt med ulike deler av helsevesenet. Til tross for at det finnes mye forskning har vi fortsatt mangelfull kunnskap som kan støtte utvikling, gjennomføring og evaluering av løsninger for forbedring av tjenestene for personer med ulike og komplekse behov på sykehus og på tvers av helsetjenester.

Mål

Det overordnede målet med avhandlingen var derfor å utforske implikasjonene for sykehuspraksiser knyttet til det å sørge for sammenhengende pasientforløp for pasienter med langvarige og komplekse behov i skjæringspunktet mellom politikk, praksis og pasientopplevelser. Dette ble operasjonalisert i tre delmål. Det første omfattet norske myndigheters introduksjon av nye lovpålagte koordinatorroller i sykehus (studie I). Det andre var rettet mot å utforske erfaringer hos helsepersonell på sykehus som tar på seg koordineringsansvar for pasienter som trenger forløpskoordinering (studie II), og det tredje dreide seg om hvordan pasienters erfaringer med sammenheng i helsetjenestene gjennom en sykdomsperiode står i forhold til idealer for personsentrerte og integrerte tjenester (studie III).

Metode

Tre kvalitative studier ble gjennomført: En diskursanalyse av myndighetsdokumenter (studie I), en intervjustudie av helsepersonell (studie II), og en kombinert studie der intervju med pasienter omkring deres eget helsetjenesteforløp ble analysert i forhold til et rammeverk for personsentrerte tjenester (studie III).

Resultat

I studie I fant vi at fragmenterte tjenester og mangel på stabile og ansvarlige fagpersoner for pasienter med komplekse tjenestebehov var definert som et ansvarsproblem. Sammenheng og kontinuitet skal sikres gjennom utvidet personlig ansvar for klinikere i roller som individuelle pasientkoordinatorer. Koordinatorenes ansvar og oppgaver er uttrykt gjennom overordnede

idealer om sammenheng, oversikt og brukermedvirkning. Det er sagt lite om på hvilken måte variasjonen i kompleksitet og behov for bistand til kontinuitet skal håndteres i ulike sykehuskontekster.

I studie II fortalte erfarne fagfolk om hvordan de 'lå ett steg foran' og 'forhandlet' løsninger for sammenheng og kontinuitet for de pasientene de vurderte trengte det mest. De utviklet personlige og konteksttilpassede koordinatorroller, og justerte ambisjonsnivået ut fra hva de vurderte som gjennomførbart basert på sin egen personlige autoritet og tilgjengelige ressurser.

I studie III, fant vi at pasientene evaluerte sine forløpserfaringer i relasjon til langsiktige personlige mål. Evalueringen viste tilfredsstillende kvalitet på enkeltstående helsetjenester. Imidlertid framkom svikt i overganger, mangel på helhetlig tilnærming og forløpsperspektiv når erfaringene ble vurdert opp mot et rammeverk for målstyrte, personsentrerte og integrerte tjenester.

Konklusjon

Den norske politikken med lovpålagte koordinatorroller i sykehus bruker argumenter relatert til sammenhengende pasientforløp som er i tråd med hva pasienter uttrykker ønske om. Imidlertid opplevde pasientene med sammensatte tjenestebehov, og helsepersonell med koordinatoransvar, betydelige utfordringer knyttet til realisering av disse idealene.

På grunn av stor variasjon i behov og mål hos pasienter som trenger støtte til sammenheng i sine forløp, og at koordineringspraksisene er konteksttilpassede, argumenteres det for at koordineringstiltakene må skreddersys for å imøtekomme den unike kombinasjonen av individuelle behov og tilgjengelige koordineringsressurser i den enkelte situasjon. Det presenteres en tilnærming til hvordan disse behovene og ressursene kan identifiseres.

For å realisere bærekraftige løsninger som skal sikre sammenheng, oversikt og medvirkning for pasienter med komplekse tjenestebehov, foreslås det at forløpsinfrastrukturer innføres også for denne pasientgruppen. Disse må bygge på noen strukturelle krav, men likevel tillate individuell variasjon. Anbefalte elementer er et flytskjema som viser ideelle forløpsfaser, obligatorisk dokumentasjon og rapportering på definerte punkter, systemer for tilbakemeldinger fra pasientene under prosessen, og dedikerte forløpskoordinatorer.

1 Introduction

This thesis focuses on challenges in the intersection between policies, practice and patient experiences related to continuity of care for patients in need of complex or long-term, and coordinated healthcare services. The point of departure is Norwegian policy on continuity of care, and hospitals as the setting for coordination work. In the last paper, where we explore patients' experiences of continuity of care, the study is not limited to the hospitals' role or the hospital context.

This work is influenced by the Norwegian Coordination Reform that was implemented in 2012. The Coordination Reform highlighted pathways and coordinators as measures for ensuring continuity of care in the future health and care services:

The pathway approach will help to orient all systems and services toward assisting the individual with coping with life or restoring functioning. The Government recommends that patients with needs for coordinated services should be assigned one person as a contact point for all the services

(Helse og omsorgsdepartementet, 2009, pp 5-6).

Thus, a central political aim was that the patients should experience coherent care trajectories and have their own responsible and available coordinator representing the healthcare services. This represented a further development of previous policies that has been introduced since 2000, dictating increasingly stronger legal regulations for different coordinator roles along with a statutory right to individual care plans for patients with complex or long-term needs (Kjellevoid, 2013; Spesialisthelsetjenesteloven med kommentarer, 2013). Nevertheless, the rationale for and development of these policies has not been fully scrutinized. Neither is it known how healthcare professionals in hospitals experience these continuity-of-care measures.

The Coordination Reform, like other related policy initiatives, has patients as the ultimate target. In this thesis, the patient group targeted for the coordination measures, are persons with chronic conditions, multiple health problems, severe diseases, disabilities and challenging personal situations resulting in long-term needs of healthcare from various

providers and units. As there is paucity in knowledge about whether patients' experiences are aligned with the ideals of continuity of care, this is also investigated.

1.1 Personal background and motivation

I have more than 20 years of experience from clinical rehabilitation settings in specialized and primary healthcare as an Occupational Therapist and leader, as well as from various roles within quality development of interdisciplinary rehabilitation practice. The last five years prior to this PhD-study, I worked at the system level in an advisory position in specialized healthcare. One of my responsibilities was to support hospitals in establishing coordinating units (CUs). Later my work also included support to the CUs in implementing individual care plans and care coordinators in hospitals according to national regulations and guidelines for patients with complex or long-term needs of coordinated healthcare services.

From these different positions, I have met many patients expressing needs of competent, coherent and long-term support in the process of managing their disease and/or functional limitations, as well as to cope with being dependent on healthcare services in their everyday lives. In the same period, I have experienced that specialized hospital departments (e.g., rehabilitation and geriatrics), staffed and organized to support patients with this type of complexity in an individualized and long-term perspective, have been downsized and reorganized. Parallel to this, we have seen a development towards decreased length of hospital stays in all types of hospital departments.

The hospitals became legally obligated to appoint patient care coordinators for patients with complex or long-term needs of coordinated services from 2012. The coordinating units in the hospitals have developed and disseminated procedures as well as offered training and supervision to clinicians and leaders in order to implement the new coordinator role. Nevertheless, the hospitals have struggled and often failed, to realize this coordinator role in clinical hospital practices.

My primary interest and motivation for exploring these care coordination challenges at the intersection between policy, practice, and patient experiences are founded in a healthcare delivery perspective. It is my hope that the systematic study of these challenges in light of the

current research literature may ultimately contribute to improving hospitals' ability to fulfil their obligations to patients with complex or long-term service needs.

1.2 Outline of the thesis

Following this introduction, the background chapter outlines the conceptual frame relevant to the scope of the thesis, as well as literature more specifically relevant for the three papers. Here included; the Norwegian healthcare context and reform measures aiming at continuity of care, followed by characteristics of hospitals as the setting for coordination practices and the targeted patient group for coordination efforts. In chapter three, I outline the overall aim of the thesis and the aims of the three studies. Materials and methods are described in chapter four, including how the research ethics are addressed. The results, comprising a summary of the findings from each of the three papers, are presented in the fifth chapter. Reflexivity, choice of design, as well as considerations around the analysis and transferability of the findings across the studies, are discussed in chapter six. In the seventh chapter, the main results and contribution are discussed. In the final chapter, I present my concluding remarks and suggest implications for clinical work and further research.

2 Background

Continuous specialization of professional competence, treatment and service provision has led to great successes. However, it has also resulted in increased complexity in the organization of healthcare, which in turn has led to fragmentation of services. Various measures have been introduced to overcome this fragmentation and to ensure continuity of care for patients needing care from several providers and services. Selected continuity of care measures constitute the starting point of this thesis.

2.1 Conceptual frame

Policy initiatives and reforms have used different concepts in expressing the aims and ideals, the scope of the enterprise, the organization, and the process of providing coordinated healthcare delivery that is customized to the patients' needs and goals. However, the concepts are frequently used interchangeably without clear definitions of the meaning, and this creates difficulties for policymakers, planners, managers, clinicians, and researchers (Kodner, 2009). Uijen, Schers et al. (2012) reviewed the concepts continuity of care, coordination of care and integration of care, as well as patient-centred care and case management in research literature from 1948-2009. They found that the definitions of the main concepts varied substantially over time and that they were conceptually entangled. They concluded that the patient perspective, personal relationship, communication and cooperation between providers were common themes across all the reviewed concepts.

Similarly, a recent overview of integrated care models by WHO from 2016 (World Health Organization. Regional office of Europe, 2016), pointed out the lack of unified definitions or common conceptual understandings. To establish a conceptual frame for the study, it is, therefore, necessary to review central concepts.

2.1.1 Integrated care – international policy ideal and overarching concept

In 2001, the WHO presented a strategy for the integration of healthcare to meet demographic and epidemiological changes, as well as rising expectations and strengthened patient rights

(Gröne & Garcia-Barbero). The strategy aimed at reducing costs as well as enhancing quality, healthcare access and efficiency, in addition to improving user satisfaction. WHO put forward the following definition:

Integrated Care is a concept bringing together inputs, delivery, management and organization of services related to diagnosis, treatment, care, rehabilitation, and health promotion. (Gröne & Garcia-Barbero, 2001, p. 7)

Thus, the WHO policy of integrated care encompasses methods, models and interventions for funding, administration, organization, and clinical service delivery, aiming at connectivity, alignment and collaboration within and between healthcare services (Kodner & Spreeuwenberg, 2002).

Nevertheless, the concept of integrated care has been used about integrating health and social services (Leutz, 1999), cure and care (Kodner & Spreeuwenberg, 2002), primary and secondary healthcare services and institutions (Torjesen, Kvåle et al., 2016), and as an overarching ideal for healthcare delivery (Gröne & Garcia-Barbero, 2001). Kodner (2009) explores what he calls the polymorphous nature and lack of specificity and clarity of the concept of integrated care. He suggests five dimensions to display the complexity of integrated care; foci (communities, sub-groups, patients), types (functional, organizational, professional, clinical, normative and systemic), levels (funding, administrative, organizational, delivery, clinical), breadth (horizontal, vertical) and degree of integration (linkage, coordination, full integration) (ibid.).

Kodner is not alone in trying to clarify the concept of integrated care, as a number of other frameworks have been developed for the same purpose. These have different aims, ranging from alignment of the understanding of integrated care (Edgren, 2008; Valentijn, 2016), facilitating consistent use of central concepts (Holland & Harris, 2008; Singer, 2011), or enabling comparison and evaluation of interventions (Ahgren, B. & Axelsson, 2005; Busetto, Luijkx et al., 2016; Ouwens, Wollersheim et al., 2005; Pless, Van Hoogtem et al., 2017; Van Houdt, Heyrman et al., 2013).

WHO has put forward a new definition expanding the understanding, and have introduced ‘Integrated people-centred health services’ (IPCHS) as the overarching concept. WHO uses this to envision future healthcare across the world today (World Health Organization, 2016):

Integrated health services is health services that are managed and delivered in a way that ensures people receive a continuum of health promotion, disease prevention, diagnosis, treatment, disease management, rehabilitation and palliative care services, at the different levels and sites of care within the health system, and according to their needs, throughout their whole life. (WHO Service Delivery and Safety (SDS) Department, 2016, website)

2.1.2 Continuity of care – a multidimensional concept of patient-experienced care over time

Closely related to integrated care is continuity of care, which is the core term used in this thesis.

The results from the extensive British and Canadian research programs on Continuity of care from 2000-2010 are central in the literature on continuity of care. Comprehensive literature reviews (Freeman , Shepperd et al., 2001; Freeman , Woloshynowych et al., 2007; Reid, Haggerty et al., 2002) formed the basis for common definitions and multidimensional conceptual models. Two central elements for continuity of care were formulated: Care of an individual patient, and care over time.

For continuity of care to exist, care must be experienced as connected and coherent (Haggerty, Reid et al., 2003). Further, three types of continuity were identified across disciplines; management continuity, informational continuity and relational continuity (Freeman et al., 2007; Haggerty et al., 2003). The overall results from the British program were later reviewed, and this analysis indicated that two different paradigms were in operation, as well as a third emerging paradigm shift in the conceptualizations of continuity of care (Heaton, Corden et al., 2012). In the first paradigm, the professional paradigm, continuity of care was regarded as something that could be delivered to patients as coordinated services. The second paradigm, the perspectivist paradigm emphasized that patients, carers and professionals may have different viewpoints, understandings, and preferences of what they consider as the desired continuity of care. In the emerging “partnership paradigm”, continuity

of care was understood as both a process and a product of co-creation between patients and professionals. Heaton et al. (2012) suggest that future research focus not only on how continuity of care is understood but also on how it is achieved and on which factors promote or impede its achievement in particular contexts.

In this thesis, broad enough for covering these paradigms, the frequently used definition published by Haggerty et al. (2003, p.1221) is used:

Continuity of care is the extent to which a series of discrete healthcare events is experienced as coherent and connected and consistent with the patient's medical needs and personal contexts.

In a recent practice brief about continuity and coordination of care, the WHO uses the same definition, with a few minor changes (2018). Thus, the patients' experience of care over time remains the central aspect in the conceptualization of continuity of care.

2.1.3 Care coordination – a delivery perspective

To achieve continuity of care, the care must be coordinated. Although the patient is seen as a collaborating partner, and that care coordination and continuity of care are closely related, the concept of care coordination mainly reflects the provider's perception (Waibel, Henao et al., 2012).

The landmark review of care coordination by McDonald, Sundaram et al. (2007, p. 5) identified more than 40 definitions of care coordination and related terminology. They developed a working definition by drawing together common elements from the reviewed literature:

Care coordination is the deliberate organization of patient care activities between two or more participants (including the patient) involved in a patient's care to facilitate the appropriate delivery of health care services. Organizing care involves the marshalling of personnel and other resources needed to carry out all required patient care activities, and is often managed by the exchange of information among participants responsible for different aspects of care.

The delivery perspective is also emphasized by the WHO, by presenting care coordination as one of the approaches in strategies for integrated people-centred health services (World Health Organization, 2016, p. 8):

The focus for improvement is on the delivery of care to the individual, with services coordinated around their needs and those of their families. This approach also covers improved information flows and maintenance of trustworthy relationships with providers over time.

2.1.4 Care pathways – process-organized care for groups or individuals

Continuity of care, and by implication care coordination, is frequently operationalized as coherent care pathways (Schrijvers, van Hoorn et al., 2012; Vos, Chalmers et al., 2011). The use of terminology on care pathways may be confusing. ‘Care pathway’ is used to express the patient’s progression through healthcare during a period of illness (Helse- og omsorgsdepartementet, 2009), as well as to describe an intervention, i.e. standardized work processes to ensure continuity of care (Biringer, Størkson et al., 2017).

Pless et al. (2017) define care pathways as interventions building on a process-oriented task division logic, as a way of enhancing the quality of care through identifying and improving critical points in care processes. The authoritative definition of a care pathway by the European Pathway Association (E-P-A) reflects this distinction:

A complex intervention for the mutual decision-making and organization of care processes for a well-defined group of patients during a well-defined period
(Vanhaecht, Panella et al., 2010, p. 118).

E-P-A includes clinical pathways, critical pathways and integrated care pathways in the term ‘care pathways’. They describe care pathways as an operationalization and standardization of patient-centred care, building on the involvement of patients as real partners, and pathways as norms built on evidence-based guidelines for the selected disease or patient group. Identifying resources, sequencing the activities of the professionals, as well as documentation, monitoring, and evaluation of variances and results, are other central characteristics (ibid).

However, this use of the concept of care pathways can lead to a limited understanding of the types of coordination activities that can be modelled. The use of ‘pathway rhetoric’ and the ideals of process-organized care have expanded in healthcare in later years (Axelsson, Axelsson et al., 2014; Fineide & Ramsdal, 2014). From primarily covering one diagnosis, the care pathway concept has lately been used also to encompass multimorbidity or complex service needs. From describing short intra-organizational processes in hospital departments, it has expanded to include transfers between services and across organizations over more extended periods. This expansion has led to challenges in how to define a relevant knowledge base to build the care pathway on, as well as challenges in how to delineate, develop and implement care pathways when transcending different healthcare contexts (Fineide & Ramsdal, 2014).

One way of differentiating between various care pathway models is suggested by Vanhaecht et al. (2010, p. 119). Three types of care pathways are defined based on the level of predictability of the care process and the level of agreement about the choice of treatment between the professionals involved:

- Chain models, which are useful for highly predictable processes where there is broad agreement. Examples of these are time-task matrixes for disease-specific diagnostics, elective surgery or chemotherapy.
- Hub models are relevant for less predictable processes and where multidisciplinary negotiations are needed. Here a case manager or key professional organizes the care process. This is typically seen in rehabilitation, palliative care or psychiatry.
- Web models work for the most unpredictable and complex conditions where the process needs to be continuously customized through incremental problem-solving. This is relevant when patients have complex comorbidity or unstable conditions where multidisciplinary knowledge and frequent assessments and decisions are needed.

I will refer to the chain, hub and web models by Vanhaecht et al. (2010) throughout this thesis to further clarify the understandings and to discuss the planning and organization of care pathways.

Besides, concepts including the term ‘trajectory’ are widely used in literature concerning continuity of care. Both to express the emerging sequence of events and turning points in

treatment over time for the patient, and to express the assembling, scheduling, and coordination of planned steps in patient care (Pescosolido, 2013). A more comprehensive understanding of the trajectory concept, which is relevant for this thesis, is the way it is used by (Allen):

“Care trajectory” refers to “the unfolding of patients” health and social care needs, the total organization of work associated with meeting those needs, plus the impact on those involved with that work and its organization (Allen, 2018b, p. 2).

In conclusion, the terms pathway and trajectory are used in several meanings in the literature, and so is also the case in this thesis.

2.1.5 Patient-centredness – individual needs, personal context and transfer of power

All of the concepts presented above include a focus on the patients’ involvement, individual needs, and experiences, summarised as patient-centredness or sometimes person-centredness. Patient-centred care is used widely in its own right as a hallmark of quality in policy and research rhetoric worldwide (Kuluski, Kerry, Peckham et al., 2016). Under the labels of patient-centredness, person-centredness or similar, the patient perspective and patient involvement in care have been increasingly emphasized in the literature since 1970 as a contrast to disease-centredness or a unilateral healthcare-provider perspective (Mead & Bower, 2000; Uijen et al., 2012). This reflects a movement towards taking a holistic perspective, as well as sensitivity for the importance of social, psychological, cultural and ethical issues in the professional - patient encounters (Hughes, J. C., Bamford et al., 2008).

Hughes et al. studied the use of different types of ‘centredness’. They found that client, family, patient, person and relationship-centredness, share the central features: seeing the person as an individual, trying to understand what the illness means for the particular person in his or her context, considering the persons’ values and point of view, and sharing the power and responsibility with the patient (Hughes, J. C. et al., 2008).

Taking a more societal view, WHO uses the term ‘people-centred’, covering the perspectives of individuals, the involvement of users, families and communities. It is a term used to

emphasize the need of responding to the users' needs holistically, securing access to quality health services where users co-produce their care together with healthcare providers in a way that meets their life course needs and respects their preferences (World Health Organization, 2016).

Several scholars emphasize that the central message of person-centred care is transfer of power from clinicians to patients towards more equal partnership in defining needs, planning and delivering coordinated and personalized care through a collaborative process where patients and clinicians negotiate around goals and actions (Coulter A, Entwistle VA et al., 2015; Mathers & Paynton, 2016; Spicker, 2012). Although there is collective agreement about the ideals that patients' needs should be considered in perspective of the values and unique situation of the individual, and that care should be aligned with the context in which they work and live, this has shown challenging to achieve in practice (Kuluski, Kerry et al., 2016).

Thus, there needs to be an alignment between the governing policy, how care is delivered and how it is experienced by the patients.

2.2 Policy approaches to coordinated care in a Norwegian setting

The setting for this thesis is the Norwegian healthcare system and hospitals in particular. The empirical work starts with a focus on the policies developed in Norway. It is, therefore, necessary to give a rather comprehensive introduction of the latest policy developments. The presentation gives a broad overview of the system, followed by some details that are relevant to the empirical work in this thesis.

Norway has a publicly funded healthcare system, broadly speaking free at the point of service. The system is divided in two: Specialized healthcare including the hospitals is owned and run by the state, and operated by four regional health authorities (Romøren, Torjesen et al., 2011). Primary healthcare is organized and financed by the municipalities, who have great autonomy. It comprises homecare and nursing services, nursing homes, physiotherapy, occupational therapy etc. Every citizen is entitled to a regular general practitioner (GP). The GPs are organized as private enterprises and work on contracts with the municipalities

(Røsstad, 2016). Assistance to social and economic security is organized separately from healthcare in the Norwegian Labour and Welfare Organization, which does not include home services in Norway¹.

In 2012 the Norwegian Coordination Reform (CR) was implemented under the title ‘Proper treatment – at the right time and right place’ (Helse og omsorgsdepartementet, 2009). The Coordination Reform points out three major challenges in the Norwegian health and care services:

1. *Patients’ needs for coordinated services are not being sufficiently met.*
 2. *In the services, there is too little initiative aimed at limiting and preventing disease.*
 3. *Population development and the changing range of illnesses among the population.*
- (Helse og omsorgsdepartementet, 2009, p. 4)

Central objectives of the CR was to improve collaboration between specialized and primary healthcare both on a system level and on an individual level and to transfer responsibility from hospitals to primary care for a number of services. Among other measures, the Coordination Reform introduced legal requirements of collaboration contracts between hospitals and the primary healthcare sector for 12 defined areas, as well as the statutory establishment of collaborative committees, representing both sectors, for each hospital’s region. Financial incentives were implemented, such as penalties for the municipalities when hospital discharge is delayed due to a lack of available services for the patient in primary care (Helse- og omsorgsdepartementet, 2009).

2.2.1 Pathway approach and coordinators

The CR recommended holistic care pathways across healthcare levels to achieve continuity and quality of care for the individual patient (Helse- og omsorgsdepartementet, 2009).

Holistic care pathways are defined in CR as ‘*the chronological chain of events that constitute the patients’ encounters with different parts of the health and care services*’ (ibid. p. 15).

Good, coherent pathways are characterised by that ‘*the events are put together in a rational*

¹ www.government.no

and coordinated way to meet the patient's individual needs' (ibid. p. 15). The reform whitepaper points out expected challenges related to differing goals between the hospitals' focus on diagnostics and curative treatment, while primary healthcare mainly focuses on functioning and coping (ibid.). However, no models were recommended for how to organize the desired 'coherent care pathways' across sectors. On the other hand, the clinicians were expected to assume an overall perspective of the patients' trajectory, and take responsibility for providing their services in a way that ensure a holistic pathway (Hagen & Johnsen, 2013).

In 2012, as part of the CR, the hospitals became legally obligated to appoint a patient care coordinator for patients requiring complex or long-term, coordinated services in order to secure continuity of care in the individual patient trajectory (Spesialisthelsetjenesteloven, 1999, § 2-5 a). This obligation applies to patients needing services from two or more different units and professions over time, independent of which medical condition(s) or from which hospital department the patient receives treatment (Spesialisthelsetjenesteloven med kommentarer, 2013, p. 25). Each hospital is required to establish a coordinating unit (CU), which is responsible for implementation and development of the patient care coordinator role, as well as for training and supervision of coordinators (Spesialisthelsetjenesteloven, 1999, § 2-5 b). Equal obligations were imposed on the municipalities (Helse- og omsorgstjenesteloven, 2011). Additionally, an amendment to the Specialized Health Care Act in 2016 gave patients with severe conditions the right to their own 'contact physician' in hospitals (§ 2-5 c).

2.2.2 Individual care planning for patients with complex needs

Personalized responsibility for assisting individual patients towards the goal of integrated care has characterized the Norwegian approach also prior to the CR (Ahgren, 2014). In 2001, patients with complex needs gained a legal right to an individual care plan (ICP) coordinated by one of the caregivers (Bjerkan, Richter et al., 2011). This right was a response to service users' experiences of fragmented, random, uncoordinated services and lack of user involvement in rehabilitation. The ICP is a tool with the purpose of securing a holistic, coordinated and individually adapted set of services (Breimo, 2014). The ICP is defined as a tailored personal plan built around prioritized personal goals for the patient adapted to his resources and needs (Rehabiliteringsforskriften, 2011, § 19). It is a basic requirement that the

patient has a central role in planning and prioritizing the goals and that the ICP is developed in a partnership between the patient and a multidisciplinary team of professionals from the relevant service units and sectors, led by a personal ICP-coordinator (Helsedirektoratet, 2015b). The plan describes the aims and measures, and the responsibility for each of the planned actions within a defined period (Rehabiliteringsforskriften, 2011, § 19). The ICP is intended to be a ‘master plan’ which assembles treatment plans or care plans for various conditions, and may include services across healthcare levels and other service sectors (Holum, 2012). It is the duty of the ICP-coordinator to recruit and organize the participation of relevant professionals for this work and to ensure that the plan is documented and evaluated (2015b). The main responsibility for the ICP lies in primary healthcare, but the hospitals are obligated to start the work with the plan and to participate when they are involved in ongoing treatment or follow-up. For patients needing only specialized healthcare, the hospital has the responsibility to develop the plan (ibid.). The hospitals are obligated to offer care coordinators to patients in need of long-term coordinated services regardless of if they want an individual care plan (ibid.).

2.3 Hospitals as setting for continuity of care

Providing continuity of care for patients with complex needs is particularly challenging for hospitals due to a continuous increase in the number of specialized units that are mainly organized according to medical specialties and treatment procedures. Numerous professionals involved in treatment and care of the single patient, and professionals working in shifts are also important factors (Axelsson et al., 2014; Krogstad, Hofoss et al., 2002; World Health Organization. Regional office of Europe, 2012). Furthermore, the number of in-patient days for each patient is decreasing, and the outpatient activity and day treatment is increasing both in physical and mental health hospital departments. This development is likely to continue. Both national and international policy for the future role of hospitals, point at development of hospitals towards becoming increasingly more specialized, and that rehabilitation, geriatric care and palliative care are to be transferred to primary healthcare (Helse- og omsorgsdepartementet, 2009; World Health Organization. Regional office of Europe, 2012)

2.3.1 Implementation of different pathway models in hospitals

Clinical pathways

Many hospitals have established clinical pathways for different patient groups and treatment procedures. Reviews of the research on the effect of such clinical pathways have shown that they improve patient outcomes, length of stay, and reduces cost (Rotter, Kinsman et al., 2010; Shabaninejad, Alidoost et al., 2018).

Also in Norway, there have been strong initiatives and commitments from both local and national health authorities to develop and implement such clinical pathways in hospitals (Ramsdal & Fineide, 2010). In 2015 there was a national implementation of ‘Cancer pathways’² (Helsedirektoratet, 2015a). These type of pathway projects are inspired by Danish projects, but the pathways are customized to the Norwegian healthcare context (Grimsmo & Magnussen, 2015). Twenty-eight such cancer pathways were implemented nationally in hospitals in 2015-16 (Helsedirektoratet, 2015a). These are preplanned ‘chains of care’ (Vanhaecht et al., 2010), often with pre-booked consultations and pre-organized multidisciplinary collaboration. They are designed to make the patients’ trajectories uniform and streamlined with a defined pathway timeline describing the length of each phase. Dedicated positions for cancer pathway coordinators were established for each type of cancer pathway with the responsibility of facilitating, documenting and reporting the patient flow, as well as being a contact person for the patients and securing continuity (Helsedirektoratet, 2015a).

Pathways in specialized mental healthcare and substance abuse treatment in Norway

From 2019, we see a different type of structured pathways being introduced nationally in Norway: Primarily, three generic pathways within specialized mental healthcare and substance abuse treatment will be implemented (Helsedirektoratet, 2018a, 2018b, 2018c). These pathways differ in several aspects from the cancer pathways: The logistics are not planned in detail such as in the cancer pathway model. Instead, it is the overall process of assessment, treatment, and follow-up that constitute the pathway. Pathway coordinators on a system level are given a broad responsibility to facilitate the patient flow according to the

² In Norwegian: ‘Pakkeforløp for kreft’.

planned process, to represent continuity and be available for patients, as well as to secure collaboration between primary and specialized healthcare during the process.

Locally developed care pathways, generic and for defined patient groups

Traditional disease-specific pathways are considered neither suitable nor effective for patients with multimorbidity, for patients with low predictability of care needs, or when several units, professionals and institutions are involved (Røsstad, 2016; Vanhaecht et al., 2010). Hence, various care pathways both within and between sectors have been developed locally for designated patient groups. I will present one example here: the ‘Generic care pathway for elderly patients in need of home-care services after hospital discharge’ (Røsstad, 2016). This is an integrated care pathway covering discharge planning in the hospital and post-discharge support and follow-up the first four weeks after discharge by municipal homecare and GP. This care pathway is developed in collaboration between representatives from the hospital, primary care, and patient organizations, based on a predefined framework and challenges previously identified in the local context (ibid). The pathway consists of a designed trajectory with procedures in chronological order, sorted by the responsible actors. Additionally, several checklists were developed to secure the quality of the practice at defined stages in the patient trajectory for the different actors (marked in a flowchart). One checklist was common for primary and specialized care. The other checklists regulated what to be followed up by different actors in homecare or by the GP. Critical information from all checklists was available in the daily care plan in the patient’s electronic health record in home-care (ibid.).

2.3.2 Clinical staff taking on responsibility for continuity of care

Hospital units vary when it comes to tasks and aims, staff and organization, and patients’ needs are diverse and at times unpredictable. A significant proportion of healthcare work cannot be covered by standardized pathways and protocols, and thus depends on the emergent organization in clinical practice, or through other measures (Allen, 2018b; Schrijvers et al., 2012).

Clinicians in formal roles as coordinators

One approach is the implementation of formal roles as coordinators in hospitals, as is the case in Norway (see above). Although the coordinators are given a formal role, they still have a

challenging task. To coordinate services and information within the hospital and with external services, to follow up the patient before, under and after hospital stay, to contribute to the individual care plan, be a contact person for the patient on behalf of the hospital, and to secure information and dialogue with the patient (Spesialisthelsetjenesteloven med kommentarer, 2013) .

Several studies of such free-standing coordinator roles, confirm barriers and needs for negotiations about solutions, resources and mandate (Struwe, Baernholdt et al., 2013; Walsh, Harrison et al., 2010; Yates, 2004), as well as the necessity of developing organized innovations to solve the challenges (Miller 2000). Moreover, there is often a need for extended competence (Bradway, Trotta et al., 2012; Nutt & Hungerford, 2010; Vuorinen, Heino et al., 2009). For coordinators working with patients with the most complex conditions, the web model presented above (Vanhaecht et al., 2010), describes an ideal working situation, where multidisciplinary resources are activated based on a stepwise process with frequent team meetings.

Coordination as emergent organization in clinical practice

Even if there are a number of measures to ensure continuity of care in hospitals, as outlined above, there are a lot of informal coordination work going on in the hospital units as part of the daily work of nurses, physicians, and other professionals. In some specialized departments, e.g., for rehabilitation and mental healthcare, multidisciplinary teamwork built around individual patient goals in a pathway perspective may be the standard way of working. This is one example of the hub model for care pathways (Vanhaecht et al., 2010), where one clinician has a role as a key person in organizing the care process. In other hospital units; the staff, the activities and work organization are designed to handle core activities as surgery or advanced medical diagnostics and treatment.

Davina Allen has investigated hospital nursing practices over several years. Coordination, as when nurses create continuity for patients across shifts, departments and institutions, is dependent on broad experience and context-specific competence (2014). Allen shows how this type of organizing constitutes a considerable part of the nurses' work and points out that emerging trajectory-organizing work is poorly visible and lacks formal recognition (2018b). Hence, the clinical management has not adequately supported this work (ibid.).

2.3.3 The policy and practice of coordinator roles in hospitals

As outlined above, there are several challenges and different solutions to ensuring continuity of care in general, and in hospitals particularly. Among areas least studied, are the roles of coordinators and staff taking on coordination work (Doessing & Burau, 2015). This concerns both the policies developed and everyday practical work.

In Norwegian hospitals, clinical pathways are implemented parallel to the coordinator roles. (Helsedirektoratet, 2015a). There are overlapping aims and shared rhetoric between these two types of initiatives. Both approaches emphasize the role of pathway coordinators and continuity of care. Nevertheless, the contrasting solutions that are designed for the different target groups indicate that the problems to be solved are conceptualized differently. Analysis and critical reflection on how the policies frame the problems and solutions are needed to enhance the understanding of the challenges in translating these policies into practice, as well as to clarify similarities and differences between these two contemporary approaches.

This is connected to how coordination work is carried out by the staff in hospitals. The introduction of formal coordinator roles for clinicians in hospitals challenges healthcare practices at the intersection between daily organizational work, that is already going on in the wards, and the new and broader responsibility of coordinating pathways across departments and sectors over time. In order to plan and implement the new and extended coordination responsibility in diverse hospital departments, there is a need for enhanced knowledge on how health professionals in hospitals in their ordinary practices, across patient groups and healthcare contexts, define, realize and experience coordination activities aiming at continuity in the care trajectories for patients with complex needs.

2.4 Patients with complex or long-term needs of care – prevalence and experiences

Complexity of healthcare needs have been described with reference to multimorbidity (the number and type of the patient's diagnoses or conditions), to resource utilization and consumption of services (system perspective), or to the totality of the patient's individual life

situation including psychosocial or contextual factors and the person's healthcare experiences (multidimensional perspective) (Schaink, Kuluski et al., 2012).

The National Institute for Health and Care Excellence (NICE) has the following definition of multimorbidity.

Two or more long-term health conditions, which can include defined physical or mental conditions such as diabetes or schizophrenia, ongoing conditions such as learning disabilities, symptom complexes such as frailty or chronic pain, sensory impairment such as sight or hearing loss, or alcohol and substance misuse.

(The National Institute for Health and Care Excellence (NICE), 2016, p. 5)

Multimorbidity is a strong driver for healthcare utilization, and often entails long-term healthcare needs, which

... require a complex response over an extended time period that involves coordinated inputs from a wide range of health professionals and access to essential medicines and monitoring systems, all of which need to be optimally embedded within a system that promotes patient empowerment. (Nolte & McKee, 2008, p. 1)

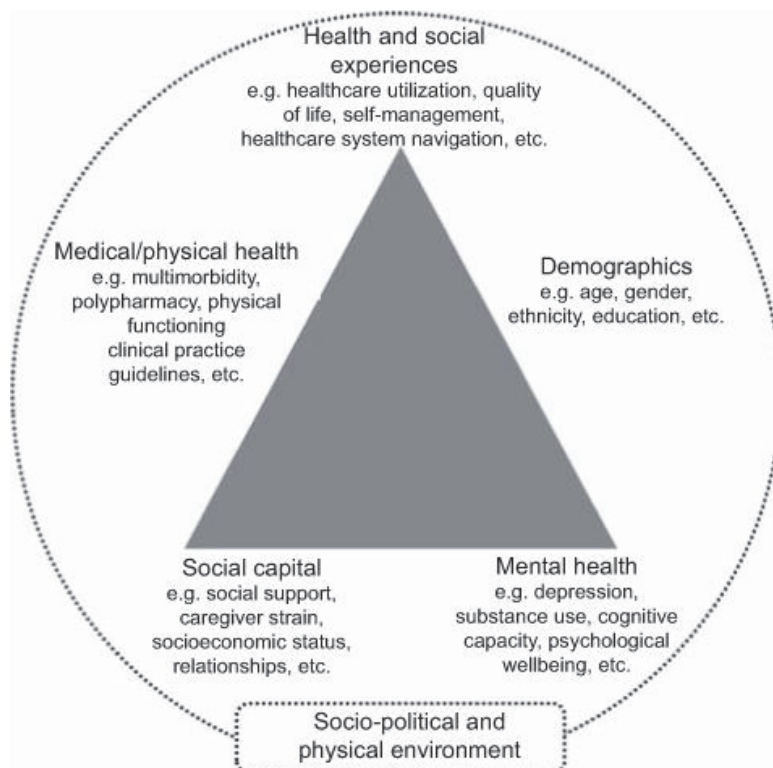
Even if multimorbidity is central, there are other types of criteria applied to identify patients with complex healthcare needs. The criteria defining which patients are entitled to a contact physician in Norwegian hospitals are severe disease, injury or conditions leading to the risk of malfunction or premature death, as well as an expected progression of physical and/or psychological consequences or uncertainty associated with severe conditions (Helsedirektoratet, 2016). Other criteria are that they need hospital treatment in more than 3-4 days, and/or more than one follow-up consultation (Helsedirektoratet, 2016).

The group for whom Norwegian hospitals are obligated to appoint patient care coordinators, on the other hand, is defined by the need of complex or long-term and coordinated services (Spesialisthelsetjenesteloven med kommentarer, 2013, p.25). This is operationalized as services from multiple treatment units, from different departments in a treatment unit and several professions (ibid.), thus representing a 'system perspective'. Hence, who has the right to coordinator support, is therefore influenced also by how healthcare services are organized.

E.g., if there are no integrated services available, the healthcare system factors themselves will be the triggering factor for the patients' healthcare rights.

Hence, a range of factors has to be taken into consideration to identify persons with complex healthcare needs. Schaink et al. (2012) have developed a multidimensional complexity framework based on a scoping review that illustrates this and summarizes some key characteristics of this patient group. The framework captures five dimensions of variation in these groups of patients (Fig.1). The Complexity Framework includes both a physical and a mental health dimension (disease/functioning), demographics (age, gender, ethnicity, education, etc.), and social capital (support, caregivers, economy, relations), as well as the individual's health and social experiences and resources. Lastly; factors in the socio- political and physical environment.

Figure 1. The multidimensional Complexity Framework by Schaink et al. (2012, p. 5).



2.4.1 Prevalence of patients with complex healthcare needs

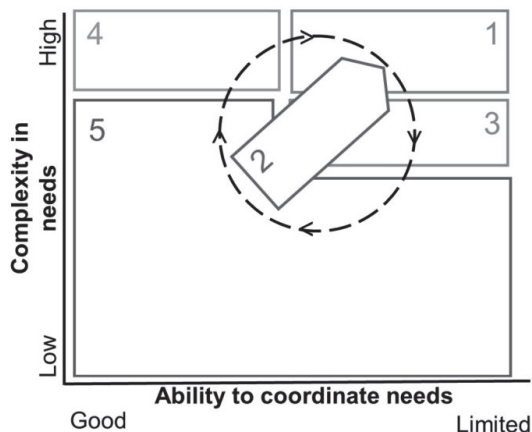
While the prevalence of specific diagnoses can be estimated as they are available in health records and registers, it is more difficult to estimate the number of patients with complex healthcare needs when these are attributed to other individual factors in the patients' situations, or characteristics of the healthcare services.

Prevalence studies on multimorbidity vary widely due to different operational definitions, types, and numbers of diagnoses included, as well as to the study methods (Fortin, Stewart et al., 2012). In the 2012 review, the largest differences in prevalence were observed at age 75; ranging from 13% to 72% in the general population. In a Lancet publication of a cross-sectional study of multimorbidity and comorbidity of physical and mental disorders in 1.8 million adult patients registered in Scottish medical practices, Barnett, Mercer et al. (2012) found that 23% were multimorbid, in the meaning of having two or more disorders. However, among these, many are capable of organizing their healthcare needs themselves (Myndigheten för vård- og omsorgsanalys, 2016).

A system approach to estimating the prevalence of patients with complex healthcare needs is to focus on the use of services: Which patients have the most frequent and costly healthcare consumption. 2-5% of hospital patients are characterized by high risk and complexity. Statistics for the Norwegian South-East health region showed that 5% of the patients use near 50% of the resources in specialized healthcare and that 1% use about 22% hospital services (Nilsen, 2018). These patients are most often those with chronic conditions, multiple diseases, and comorbidity.

A Swedish report used a multidimensional approach to identifying groups in need of coordination based on the complexity in the persons' coordination needs on the one hand, and the individual's ability to participate in, or take care of the coordination of their own care on the other hand (Myndigheten för vård- og omsorgsanalys, 2016) (fig.2). The complexity of needs dimension comprises both the number and types of services needing coordination for an individual, as well as organizational factors facilitating or complicating coordination. The individual's ability dimension can be influenced by illness, as well as cognitive, physical and mental health function or disability.

Figure 2. The complexity of needs and ability to coordinate needs. (Myndigheten för vård- og omsorgsanalys, 2016, p. 10).



The estimated size of the different groups is based on the total Swedish population's consumption of health and care services.

1. Persons with complex needs and limited resources to participate in the coordination of their care (11%).
2. Persons with acute illness with a rapid course that affects the individual's possibilities for participation (1%).
3. Mainly physically healthy individuals who have reduced abilities to participate in coordination due to, e.g., mental health issues or cognitive disabilities (8%).
4. Persons with complex needs, but with resources to participate in coordination (11%).
5. Mainly physically and mentally healthy individuals (61%).
6. Eight percent remained uncategorized after the Vårdanalys' estimation of general groups (ibid. p. 63).

In addition to estimating the scope of coordination needs, this model contributes to visualizing the diversity of profiles of those needing coordinated services. Their needs are composed of various combinations of disease-related factors, system factors, and personal factors. Moreover, the individuals are likely to move both within and between these groups over time (Myndigheten för vård- og omsorgsanalys, 2016).

2.4.2 Experiences with and desires for healthcare in patients with complex healthcare needs

Although it is difficult to give a precise estimate of the number of persons with complex healthcare needs, they constitute a sizable group who can be expected to have challenging encounters with the healthcare services. These challenges concern both the burden of the condition itself and the burden of treatment.

‘Burden of treatment’ is a concept describing the work that patients with chronic disease do to manage and follow up the monitoring, treatment, and care of their symptoms, illness or disability (May, Eton et al., 2014). The burden of treatment comes on top of the burden of the illness itself and demands resources both from the individual and their networks (ibid.). Treatment burden, examined from the perspective of patients with stroke (Gallacher, Morrison et al., 2013) and heart failure (Gallacher, May et al., 2011), has been found to include challenges related to understanding treatment and medication, the organization of care, coping with discontinuity and inadequate communication.

Qualitative studies exploring patient healthcare experiences show that patients with complex needs often experience either lack of treatment plans (Berntsen, Høyem et al., 2014), or multiple and conflicting treatment plans (Bayliss, Edwards et al., 2008). Still, elderly patients with multimorbidities expressed a wish for an individualized process where the care supports their unique combination of health issues and dynamically handles shifting problems (Bayliss et al., 2008).

Having a navigator or coordinator to represent consistency and responsibility, to organize and negotiate continuity of services was highly valued by hospitalized patients with complex needs (Kuluski, K., Hoang et al., 2013). However, Waibel et al. (2012) found that some patients sacrificed personal continuity if this helped them getting faster access to services, or admission to healthcare providers that they expected could provide a new perspective or second opinion on their situation. What seems to be central for many patients, is being involved and sharing responsibility for the care (Waibel et al., 2012), being seen and treated as a whole person, acknowledged and respected, and cared for with authentic empathy (Greenfield, Ignatowicz et al., 2014).

Despite the growing knowledge of the increasing amount of people with complex healthcare needs, our healthcare systems are still mainly configured according to a single disease framework (Barnett et al., 2012; Nolte & McKee, 2008). Central international actors like the WHO, as well as studies reflecting the patients' perspectives, advocate the need of implementing new models of care based on ideals of person-centred and integrated care for this patient population (Greenfield et al., 2014). The patients experience care in the context of their life situation and not from the professional or system perspective (May et al., 2014). In order to investigate whether the ideals of more person-centred and integrated healthcare are achieved in today's healthcare services, there is a need to evaluate patients' experiences through their healthcare trajectories within the frame of their life situation and in relation to the stated ideals.

3 Aim of thesis and studies

The overarching aim of this thesis was to explore implications for hospital practices in realizing continuity of care for patients with complex or long-term needs, at the intersection between policy, practice, and patient experiences.

3.1 Aims of studies

The main aim of the thesis was operationalized into the following study aims:

1. To explore discursive aspects of Norwegian policy documents that legislate two coordinator roles in hospitals to ensure coherent care pathways for patients with complex or long-term healthcare needs. (Paper I)
2. To investigate the experiences of health-care providers, both in designated roles and from clinical staff, who take on coordination responsibility to ensure continuity of care for patients with complex needs in various hospital settings. (Paper II)
3. To explore, apply, refine and operationalize a 4-stage goal-oriented quality of care framework aiming to capture the experiences of person-centred integrated care for persons with multimorbidity in their individual pathway. (Paper III)

4 Methods

This thesis comprises three qualitative studies. The first is a discourse analysis of policy documents. The second is an interview study with healthcare professionals. The third is an evaluative analysis of individual patient pathways, based on individual interviews with patients.

Based on our aims of exploring experiences of healthcare providers (study II) and patients (study III), and of interrogating the understandings inherent in policy on continuity of care (study I), qualitative research designs were chosen. Qualitative methods are recommended when the aim is to investigate personal experiences (Kvale, Anderssen et al., 1997) and to enhance the understanding of complex phenomena in their context (Carter & Little, 2007; Malterud, 2013). An overview of aims, designs, data sources and analyses in the three thesis papers is presented in table 1.

Following an overview of the three studies, the design, data sources, data collection, and analysis are presented separately for each study. The final section of this chapter deals with ethical and privacy issues.

Table 1. An overview of aims, designs, data sources and analyses in the three thesis papers

	Study I. Policy Paper I	Study II. Practice. Paper II	Study III. Patient experiences. Paper III
Aims	Explore discursive aspects of policy legislating two statutory coordinator roles in hospitals	Investigate experiences of health-care providers, taking on coordination responsibility to ensure continuity of care for patients with complex needs in various hospital settings	Explore, apply, refine and operationalize a framework for the evaluation of patient-centred integrated care in individual patient pathways
Study design	Critical discourse analysis	Descriptive cross-case analysis	Evaluative review employing a combined approach (see below)
Data sources	Policy documents: Acts, regulations, guidelines, and whitepapers (1997-2016) (n= 10)	Interviews with healthcare professionals across hospital contexts (n=16)	Patients' health records and individual semi-structured interviews with patients (n=19)

Data analysis	Discourse analysis; ‘What’s the problem represented to be?’ (Bacchi, 2009)	Systematic text condensation (Malterud, 2012)	Combined approach: Inductive coding and application of a goal-driven care planning framework (Ritchie & Spencer, 2002)
Operationalization of continuity of care	Continuity of care as policy; ‘coherent care pathways’	Continuity of care as practice; ‘pathway coordination work’	Continuity of care as patient experience; ‘person-centred integrated care’

4.1 Design, data, and analysis for each study

4.1.1 Paper I

Policy documents introducing patient care coordinator and contact physician roles in hospitals were analysed according to Bacchi’s discursive approach; ‘What’s the problem represented to be?’ (WPR) (Bacchi, 2009, 2016).

According to Bacchi the aims of the WPR approach to policy analysis is to understand both how governing takes place and the implications for those who are governed (2009, p. ix). Our focus has been on analysing possible implications for the healthcare professionals responsible for implementing this policy. How might their work be affected by the way the ‘problems’ to be solved are constructed in the policy? Here, the word ‘problem’ refers to *‘the kind of change implied in a particular policy proposal’* (Bacchi, 2009, p. xi)³. Discourse is understood as a ‘meaning system’ or framework, which enables particular promises and policies to be developed. It consists of assumptions, values, presuppositions and conceptual logics (Bacchi, 2009). The WPR-approach builds on the premise that every policy proposal contains an explicit or implicit diagnosis of the ‘problem’ to be solved. In this perspective, a policy is not understood as presenting solutions to problems that are objectively given. Moreover, the ‘problems’ to be solved are constructed as part of the policy-making process.

³ In line with Bacchi, we use quotation marks around the word problem when it is used in this particular meaning (Bacchi 2009, p. xi)

The WPR-analysis aims at making the implicit ‘problems’ explicit, thus enabling more systematic examination.

Data sources

Our entry to the field was the law paragraphs in the Specialized Health Services Act (Spesialisthelsetjenesteloven, 1999) covering the two coordinator roles. We supplemented with the regulations (Rehabiliteringsforskriften, 2011) and directives (Spesialisthelsetjenesteloven med kommentarer, 2013) encompassing guidance concerning the patient coordinator role. Further, we included a law proposition presenting amendments to the coordinator role and introduction of the contact physician role (Helse- og omsorgsdepartementet, 2015). The chapters in the national guidelines for rehabilitation and coordination covering the patient care coordinator role Helsedirektoratet (2015b) was then included, as well as national guidelines for the contact physician (Helsedirektoratet, 2016). Finally, the parts of four whitepapers were added to provide historical background and context (Helse- og omsorgsdepartementet, 2009; Helse og omsorgsdepartementet, 2015; NOU 1997: 2, 1997; NOU 2005: 3, 2005). Only the sections of these papers that dealt with the coordinator roles in question were used in the analysis.

Data analysis

First, the central characteristics of each of the two coordinator roles were mapped, based on full-text readings, according to dimensions that were inductively developed during the process.

The next step was to apply the first two of Bacchi’s six guiding questions for the WPR-analysis: ‘What’s the problem represented to be’, and what presuppositions or assumptions underlie this representation of the ‘problem’? (Bacchi, 2009, p. 2). First, the full text was read in the light of these questions, subsequently the results were validated against central paragraphs that had been identified through a process of text searches building on central concepts from the mapping process. ‘Answers’ to the guiding questions were recorded in memos together with analytic reflections. These were discussed among the authors, and an analytical matrix was made in a spreadsheet. Finally, the questions; what is left silenced, and which effects are produced by this ‘problem representation’, were applied.

4.1.2 Paper II

This was a qualitative study with semi-structured individual, duo and group interviews.

Participants

The aim was to include health-care providers who had either formal or informal coordination responsibilities and/or roles for ensuring continuity in care pathways for patients with complex needs. Since the study was conducted in the perspective of two statutory coordinator roles under implementation across patient groups and hospital units, we sought variation in the participants' profession, employment position, and work experience as well as in patient groups within their responsibility. We wanted to reach professionals who might be candidates to fill these coordinator roles.

The recruitment was carried out through the coordinating units (CU) at different hospitals across Norway. The CUs were contacted and asked to identify candidates based on given criteria, who were willing to participate. The results from a nationwide survey on Norwegian hospitals' implementation of the patient care coordinator role⁴ were used to select which hospitals to include. The CUs approached leaders in the relevant hospital units. Those who accepted were contacted by the researcher with a letter of information about the study including a consent form. The recruitment was conducted as a stepwise process in order to secure the intended variation.

Data collection

Individual interviews were conducted with the participants in dedicated coordinator positions, a duo interview with two persons sharing a coordinator position, and group interviews with clinicians taking on coordination responsibilities in clinical practice.

All interviews were semi-structured, and the following questions guided all interviews: What do you define as coordination work aiming at continuity of care for the patient? How do you perform this type of coordination work? How do you experience being a coordinator or taking on coordination responsibility? The interview guide is presented in the Appendix.

⁴ Conducted by AH in August 2014. Unpublished.

Interviews were audio recorded and transcribed verbatim, and reflection memos were written immediately after each interview.

Data analysis

Ten hours of interviews, 198 pages of transcribed text, were analysed following the four steps of Systematic Text Condensation (STC) as described by Malterud (2012). STC is a systematic procedure for qualitative cross-case analysis. Although inspired by Giorgi's psychological phenomenological analysis, Malterud points out that STC may also be used when the approach is descriptive like here (2012, p. 796). We considered this as an appropriate analysis in our study in light of our attention to variation in the participants' experiences of coordination work in hospitals.

In step one, preliminary themes were formulated based on repeated readings of the interview transcripts. Eleven themes were initially formulated, based on the authors' individual readings. The author group negotiated the themes between them, resulting in that the eleven themes were further revised to seven.

In step two, meaning units (the smallest text elements from the interview transcripts that were relevant for the research question) were coded into groups and subordinated to the seven themes. The themes were successively reduced to three after further negotiations of codes and themes within the author group.

In the third step, the content of all the included meaning units within each code group was condensed into one paragraph. These text paragraphs formed the basis for structure and content in the presentation of results. Quotations from the interview transcripts were selected to illustrate the themes.

The fourth step included further refinement of the themes through the process of writing the result section of the paper. Ultimately, the final text was validated against the interview transcripts.

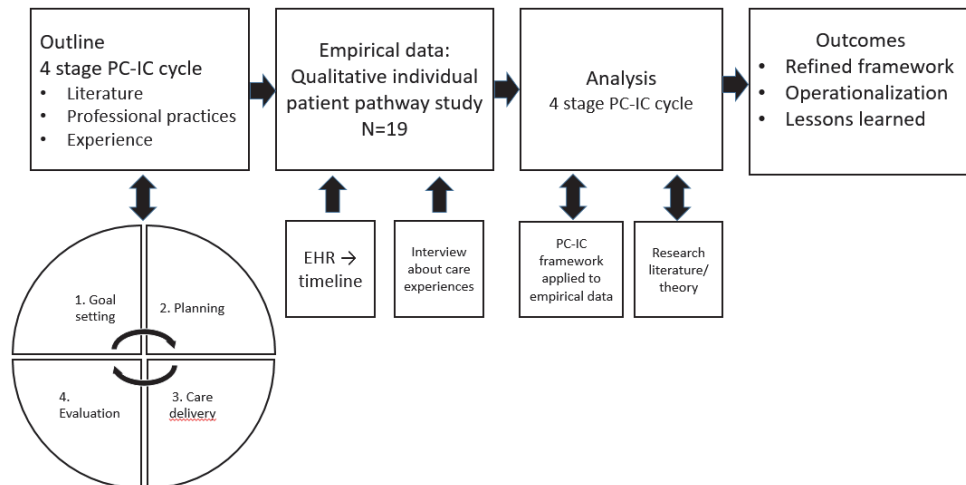
4.1.3 Paper III

The third study was a qualitative evaluative study of patient-experienced quality of care relative to ideals of patient-centred and integrated care. This combined approach was chosen to allow focusing on both the informants' particular experiences of continuity and quality of the healthcare events in their trajectory, and to analyse these data in light of ideals for goal-directed and person-centred integrated care.

To operationalize the patient-centred integrated care ideals, we started with a general goal-plan-delivery-evaluation framework. Inspired by goal-oriented chronic care (Krasny-Pacini, Hiebel et al., 2013; Vermunt, Harmsen et al., 2017) and previous research on goal setting (Berntsen, Gammon et al., 2015), we developed this into a 'four-stage goal-oriented PC-IC cyclical process' by describing each stage in more detail (see paper III, background section, p. 2).

The chosen analytical approach entailed an initial thematic coding of the patient experiences that were obtained through interviews (Ritchie & Spencer, 2002). The framework was then refined in the process of going back and forth between the thematic analysis of the interview data and the categories of the developing framework which were successively rephrased and modified. Thus, the application of the framework and its refinement were parallel processes. An overview of the stages of the research process in this study is presented in figure 3.

Figure 3. Stages of the research process in study III



Participants, recruitment and data sources

Data from two study populations were included; the Connect and the Troms-Ofoten studies. Both studies included participants with complex or long-term healthcare needs representing a wide range of experiences with healthcare.

The local cancer nurse recruited potential candidates for the Connect study. Care providers in hospitals and municipalities or local patient organizations recruited participants for the Troms-Ofoten study. Both studies intentionally sought a diversity of participants with chronic conditions in terms the types of conditions (e.g., multi-morbidity, severity, stages of treatment), context (e.g., type and the number of services) and demography. Recruitment was conducted as a stepwise process, according to inclusion criteria provided to the recruiters by the project.

Candidate participants were presented with an information letter about the study, as well as an informed consent form to sign if they chose to participate in the study. The research team contacted those who had signed the consent form. For the under-age child, the child's parents consented to participate in the study on the child's behalf.

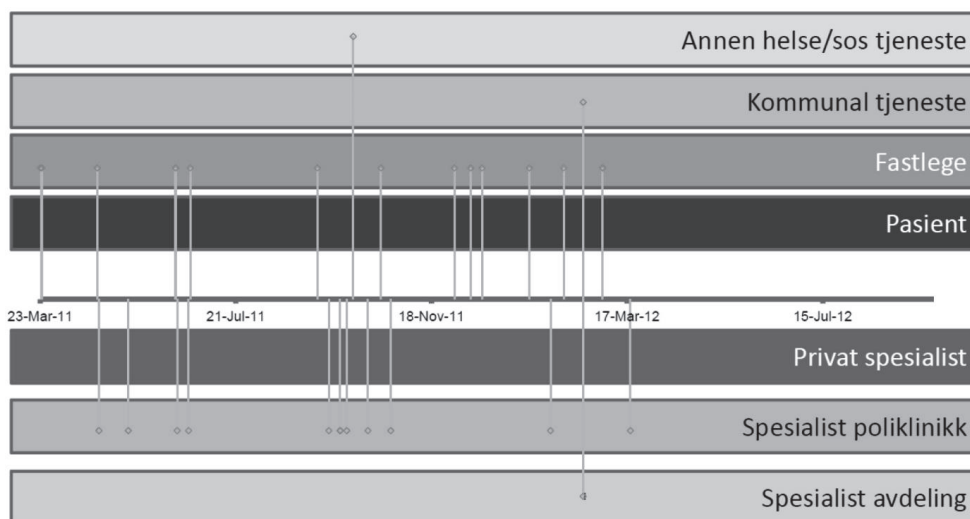
Two types of data sources were included: 1. Documentation of clinical encounters from the informants' patient health records in the hospital, at the general practitioner, and nursing services, respectively. 2. Data from individual semi-structured interviews about care experiences. The interview guide is presented in the Appendix. The bulk of the interview was spent on a shared review of the events in the individual patient's pathway, which each patient identified as important to him/her. For each important event, we discussed the nature of the event, why the patient judged it as important, the patient's evaluation of the event and the basis for this evaluation. Towards the end of the interview, we also asked the patient to evaluate their entire individual pathway.

Additionally, research literature and theory were repeatedly drawn upon as part of the analysis process and the process of refining the PC-IC framework.

Analysis

The individual clinical encounters with primary and specialized healthcare were presented on a timeline map (Fig.4) for each informant based on the reviews of the patient health records. These timelines were used as the point of departure for exploring the patients' experiences in the interviews.

Figure 4: Example of an individual patient pathway timeline. The primary and secondary care contacts are visualized above and below the timeline, respectively.



(Berntsen et al., 2014, p. 68)⁵

A synopsis was made of the interview with each informant based on full-text reading of the interview transcripts. Further, these synopses were negotiated between the authors. Salient themes were agreed on, and quotes from the interviews were chosen to illustrate the themes. Next, the themes were sorted by the initial version of the 4-stage goal-oriented PC-IC process framework. Subsequently, the PC-IC framework was refined through rephrasing, modifying,

⁵ The patient's timeline with dates is in the middle. The points indicate healthcare events in primary care above, and in specialized care below the timeline. From the bottom and up the healthcare units are: Specialized inpatient unit, specialized outpatient unit, private physician, (patient,) regular GP, municipal homecare and nursing services, other municipal health or social services.

splitting and merging elements in a dynamic process when going through the individual patient pathways. The refinement of the framework included 1) developing ideal descriptions for each phase, and 2) formulating key questions to assist evaluation of each phase. Finally, a list of relevant literature was added to each PC-IC stage. The PC-IC ideal was then re-applied to all informant data, to ensure consistency in coding across participants.

4.2 Ethics and formal requirements

Presentation of research should be transparent and reflexive regarding the research process and ethical issues related to the collection and publication of participants' personal experiences (Kuper, Lingard et al., 2008). To safeguard the privacy and protection of the participants in all phases of the research process is a core value of research ethics (De nasjonale forskningsetiske komiteer, 2010).

The requirements for approvals and consents, and how privacy issues were handled, is presented below for each study, respectively.

The information letters to the participants and the approvals are enclosed in the Appendix section.

4.2.1 Approvals

Study I

The study of policy documents did not need any approval since all sources were publicly available on the Internet.

Study II

The interview study of hospital professionals was approved by the Data Protection Official for Research (PVO) at the University Hospital of North Norway (0441). Since the purpose was not to acquire new knowledge about health and diseases, this study fell outside the Health Research Act (2010). Thus, the study did not require approval by the Regional Committees for Medical and Health Research Ethics.

Study III

Study III builds on datasets including personal health information from electronic health records and from personal interviews from two studies including patients and persons who recently were in a patient role; The Connect study and the Troms-Ofoten study. The study protocols were submitted to the Regional Committees for Medical and Health Research Ethics (REK) for assessment in REK South East and REK North, respectively.

The Connect Study (Application # 2010/3396/REK Sør-Øst B) was approved after a process of amendment. Additionally, the project was approved by Oslo University Hospital (2011/2810) and University Hospital of North Norway (0233 Connect 2.0) regarding the implementation of the research project and how to secure privacy and data storage.

For the Troms-Ofoten-study (Application # 2011/1913 C/REK North), REK decided that the project did not require their approval since they defined the study as health service research, thus falling outside the jurisdiction of REK according to the Health Research Act (2008). The Regional Data Protection Official at the University Hospital of North Norway approved the study (0258 Pasientforløp hos pasienter med kroniske tilstander).

4.2.2 Privacy

Information letters to potential participants were developed for each of the studies and amended in cooperation with REK and PVO, respectively. The information letters covered aim, funding, and organization of the study, in addition to implications of participation, how privacy regarding personal information would be secured, description of the participants' rights to access the data collected about them, and the right to withdraw from the study at any time. The letters included an informed consent form that was signed as a confirmation of their consent to participate before data collection started.

Study II

PVO provided access to secure storage of the interview audio files, the forms with personal background information, and the identification key. The identification key was stored separately. Access was limited to AH and GB. De-identified interview transcripts with fictive names and personal characteristics removed were made accessible also for the other co-

authors. Pseudonyms are used in the quotations, and anonymity is ensured by removing personal characteristics in analysis and publications.

Study III

Since this study collected personal health information obtained through healthcare records and interviews with patients, it was subject to particularly strong ethical considerations regarding data protection.

The informed consent (Connect and Troms-Ofoten) allowed the researchers access to the patients' health records in the hospital, at the GP-office, and in home-care when this was relevant, for six months (Connect) and twelve months (Troms-Ofoten) prior to the date of consent. Additionally, the consent covered participation in an interview about their healthcare journey and collection of socioeconomic and demographic background data through a short questionnaire.

Secure storage of data was regulated by the approvals from the PVOs at Oslo University Hospital (2011/2810), and at the University Hospital of North Norway (0233 Connect 2.0 and 0258). Data storage was handled as described for Study II. Access to data was limited to the project leader and named project workers. Paper printouts and summaries from EHR were de-identified and stored in locked cabinets when not in use. These will be shredded at the termination of the project in accordance with the approvals.

5 Results

5.1 Paper I

Policies make coherent care pathways a personal responsibility for clinicians. A discourse analysis of policy documents about coordinators in hospitals

Six legal documents comprising hospitals' responsibility regarding patient coordinators and contact physicians were chosen as the primary data sources. Four whitepapers that were introducing, justifying or referring to the studied coordinator roles or their predecessors were added to provide historical background and context. An overview of characteristics for the two studied roles is presented in table 2.

Table 2. Central characteristics for patient care coordinator and contact physician

Area	Coordinator	
	Patient care coordinator (1,2,3,4,5)	Contact physician (1,4,6)
Purpose	Ensure continuity and coherence in patients' care pathways.	Enhance the quality of treatment. Contribute to patient safety, predictability and continuity in patients' pathways.
Tasks	<p>Follow up of the individual patient before, under and after a hospital stay.</p> <p>Coordinate hospital services between units, departments, and professionals around the patient.</p> <p>Be the point of contact for the patient, collaborating professionals, external service providers, and institutions.</p> <p>Secure information and dialogue with the patient.</p> <p>Contribute to progression in work on the individual care plan when this is applicable</p>	<p>Be a stable contact-person for the patient regarding medical questions.</p> <p>Be involved in treatment or follow up, and be available and inform the patient and next of kin through the course of treatment and follow up.</p> <p>Contribute that the patient trajectory develops as planned.</p> <p>Establish contact with other professionals/units if necessary.</p> <p>Be available for medical questions from primary healthcare or other professionals.</p> <p>The hospital can decide whether the contact physicians also should hold the statutory responsibilities for information to the patient and documentation in the patient record.</p>

Assigned profession	Healthcare personnel. From 2012-2015: 'Coordinator should preferably be a physician'. This requirement was removed in 2015 in an amendment of the law paragraph.	Physician with relevant competence, preferably a specialist. In mental healthcare and substance abuse treatment, contact psychologist may be appointed in place of contact physician.
Target group	Patients with complex or long-term needs of coordinated services under the Act of specialized healthcare.	Patients with severe conditions in need of treatment or follow up from specialized healthcare for a period of time.
Criteria delimiting target group	Expected needs of services for the patient from different departments, units, and professions in specialized healthcare over time, and the need for coordinated services.	The severity of the condition; risk of disability or death, comorbidity, expected progression. Duration: Need for treatment more than 3-4 days. Need of more than one follow-up consultation.
Legal status	An obligation for specialized healthcare (Specialized Health Services Act). Not a legalized right for the patient.	An obligation for specialized healthcare (Specialized Health Services Act). A legalized right for the patient (The Patients' Rights Act).
Implementation status	Various degree of implementation and knowledge in the hospitals (4). National Audit concludes that the goals are not achieved (Riksrevisjonen, 2016).	The act came into force September 2016. The hospitals are in the process of developing routines for the role as well as procedures and tools for documentation and communication (2017).

The numbers in round brackets in the table refer to the numbers of the documents in table 2, p. 4 in paper I. The abbreviation PCC is used for patient care coordinator and CP for contact physician in this table

When analysing the policy documents focusing on what was defined as being in need of change, we found that the two coordinator roles are designed to solve the following two 'problems':

- the hospitals do not provide coherent care pathways for patients with complex needs
- patients do not experience responsible clinicians who are available for them over time

Related to ensuring pathway-organized healthcare services, the responsibility of the coordinator covers three dimensions: 1) safety and quality in care, 2) organizing healthcare delivery as a process, seeing the elements of care in a broad holistic perspective and securing individualized care-planning as well as taking care of logistics and timeliness, 3) ensure that ideals of person-centred care are fulfilled.

'It is vital that patients with a severe illness, injury or disability, and also their next of kin, feel secure throughout the patient trajectory.' (Helse- og omsorgsdepartementet, 2015 p. 10)

To secure that stable and responsible clinicians are available for the individual patient over time; the policy documents presuppose that clinicians' scope of responsibility is extended in roles as coordinators. Among the coordinators' extended duties are to have the main responsibility for the patients' follow-up, maintenance of a complete overview over the patient trajectory and ensure that it develops as planned, as well as being available for the patient and representing continuity throughout the treatment pathway.

The patient must experience that the contact physician represents continuity throughout the treatment pathway. (...) The contact physician must provide the patient with information, be available, and participate in the treatment team. (Helsedirektoratet, 2016, p. 21)

About the patient care coordinator, it is said that:

The service provider who is appointed as coordinator must at all times have the main responsibility for follow-up of the patient. (Helsedirektoratet, 2015b, p. 83)

How clinicians are to fulfil their expanded roles within existing work practices is left unaddressed. System measures to support and orchestrate the individual patient's pathway (e.g., resources, infrastructure) are scarcely addressed.

The studied policy documents use a 'pathway rhetoric' that is captivating. However, these concepts are established for disease-specific clinical pathways, characterized by an intra-institutional organization and building on guidelines or a common knowledge base. Equating these different types of pathways may obscure the particular challenges inherent to creating coherent care pathways for patients with long-term needs, multimorbidity, low predictability of needs, or needing multidisciplinary follow up across service units and institutions.

We suggest that the policies' construction of the 'problem' as a responsibility issue, result in that neither diversity of patients' coordination needs, nor heterogeneity of hospital contexts is set on the agenda.

Ideals of continuity, holism, and process-organized healthcare delivery express the extended responsibility of professionals in clinical positions in roles as individual patient coordinators. This statutory scheme apparently solves an obvious problem. In effect, personally responsible coordinators become the primary instrument for achieving the goal of coherent care pathways. We argue that framing the ‘problem’ this way limits creative opportunities for discussing alternative understandings and solutions that can potentially be more effective.

5.2 Paper II

Keeping one step ahead. A qualitative study of pathway coordination work in hospitals

The 16 participants worked in 15 different departments at six different hospitals. Seven worked part or full time in designated coordinator positions while the rest had taken on coordination responsibilities without being in designated positions. Eleven nurses, two doctors, one social worker, and two health secretaries were interviewed. They had an average of 17 ½ years of health-care practice. A majority had specialized training. The participants’ work covered patients with severe brain injury, severe breathing conditions in need of assistance/technology, psychosis and various mental health problems, rare syndromes with multi-organ affection, different cancer diagnoses, stroke, substance abuse, and complex geriatric conditions.

The findings were categorized into three main themes: ‘Keeping one step ahead’, ‘Identifying and activating coordination resources’, and ‘Justifying the priority and quality standards of coordination work’.

The interviewees’ coordination activities varied from transferring follow-up responsibility to another professional, via implementing a planned pathway, to orchestrating long-term cross-sectional multidisciplinary care adjusted to complex and shifting needs across care contexts. While some limited their coordination to diagnostics and treatment within the hospital, others included services after discharge and took a broader perspective including how to manage the health challenges in everyday life.

However, common for the interviewees' coordination work was to plan for the next step, be in front of things, anticipate expected progression of the health condition and trying to predict future needs of support.

Key to the course of treatment is to set up a collaborative meeting or to start something [in primary care] to be on the case and to achieve continuity. You just need to stay in front of things – all the time. (Nurse, detox. ward)

A majority of the interviewees told of constraints in available resources that could be allocated to orchestrate care coordination. Nevertheless, they exploited accessible resources to negotiate individual solutions for selected patients whom they considered in particular need of coordination. It varied what was defined as coordination resources in different contexts. Some examples were; capacity and availability of personnel with desired competence, adequate organizational structures like interdisciplinary teamwork, relevant follow-up services and the freedom to choose their own way of working. Their access to resources was often dependent on personal autonomy and authority. In their effort to balance the coordination needs with the resources available, the interviewees seemed to adjust the continuity ambitions on behalf of their patients to what they considered doable in the relevant context.

There is no possibility in the system to register the telephone consultations or organizing work [so that this activity could generate income for the hospital]. You should be able to allocate time for coordination work. This means a lot if you are to take on a medical coordination role. (Specialized physician, children with complex conditions)

When having to expand their professional role to meet patients' need of continuity support, they justified this either by referring to mandated roles, planned pathways or guidelines, to the particularly complex needs of the patient, multidisciplinary working routines, care quality, or to their knowledge and network.

I know the patients. I know what has happened and which complications to look for. I am in a "flow zone" in a way. Moreover, when you know the others well, you know how they think, and you don't have to say so much. (Specialized physician, coordinator early rehabilitation phase after brain injury)

The informants manoeuvred in the systems through ‘knowing the name of the game’, being sensitive and responsive in the interplay with other professionals and the patients to keep one step ahead.

5.3 Paper III

A person-centred integrated care quality framework. A qualitative study of patients’ evaluation of care in light of chronic care ideals

Participants in this study were eleven cancer patients in active treatment or cancer survivors with long-term sequelae from the Connect study and eight patients with various complex conditions from the Troms-Ofoten study. Each participant had from two to ten diagnoses treated from two to twelve health services. They had an average of 28 health service visits (5-132) and 16 inpatient days (0-130) in the hospital per year. Their ages varied from nine to 76 years.

The main contribution of this study is the description of a goal-oriented process-framework for patient evaluation of person-centred integrated care, referred to as PC-IC.

The participants reviewed care quality in their individual pathways by how care had supported or threatened their own long-term health goals or life goals. They placed the responsibility for care quality and delivery on the care system, not on the individual professional. With a few exceptions, care goals and plans of care delivery beyond the treatment of single conditions were not recorded in the participants’ electronic health record (EHR). There were no records of evaluation of care delivery or goal attainment.

Based on reviews of the individual care events in the participants’ EHRs and on the participants’ reported experiences and reflections, the following quality attributes of long-term care were formulated as refinements of the PC-IC framework: The unit of the evaluation should be the long-term individual patient pathway (iPP) process, not the care event. The iPP process may be defined as consisting of four stages building on each other; 1) Personalized goal setting based on “what matters to you?” 2) Care planning aligned with goals 3) Care delivery according to a plan, and 4) Assessment of goal-attainment. Assessing the patient’s

goals and needs must be a negotiation process built on trust, allowing a wide scope including life goals that further can be translated into relevant and realistic goals of care. The individual goals should be the basis for which skills and capabilities, tasks and resources that are needed. Care integration is achieved when the skills and competencies are effectively orchestrated into supporting the care goals negotiated between the patient and the healthcare provider. The quality of the care plan depends on how well it supports the overarching goal. The quality of care delivery depends on how well it provides the planned care.

Descriptions of ideal care, key questions to facilitate systematic assessment of the patient's needs, values, and goals, together with literature references supporting the ideals and key questions, were added to each of the four stages in the framework. Through this process, a general cyclic goal-oriented framework was refined into a person-centred integrated care (PC-IC) process-framework for evaluation of individual Patient Pathways.

When this version of the PC-IC process framework was applied to the analysis of patient-experienced continuity of care, gaps in care that would be invisible with an event-based quality of care framework become apparent. This first version of the framework needs further development.

6 Discussion of methods

In this thesis, I have used different qualitative methods for each of the studies presented in the respective papers. Each paper includes a discussion of the specific methods. Here I will offer a broader discussion of the methods used, starting with reflexivity and my role in the research process. Then I will argue for the choice of design and present considerations around the analysis and transferability of the findings.

6.1 Reflexivity

Reflexivity concerns the systematic awareness regarding the influence of the researcher in the research process (Malterud, 2001, 2013). I have positioned this research within a social constructivist paradigm where social reality is understood as constructed and interpreted by the participants through their actions and opinions, and where phenomena must be understood in light of their context (Blaikie, 2009; Malterud, 2013). Within this position, the researcher is not seen as neutral, but active and participatory in the production of knowledge, co-constructing the data together with the participants. Writing and reporting are considered as part of the analytic process, as the researcher's interpretation and understanding are developing through the writing (Carter & Little, 2007). Central to reflexivity is that the researcher is reflective and transparent about her preconceptions and presuppositions, personal/ professional status, position, and relations to the field and the research participants (Kuper et al., 2008).

My background as a healthcare professional makes me an insider in many ways. Thus, I can easily communicate with healthcare professionals and relate to many of the descriptions of their practice. However, my experience is limited to physical rehabilitation departments, which differ from most other clinical contexts in hospitals in terms of work organization, multidisciplinary, and lengths of patient stays. Additionally, I have been in advisory positions supporting coordination units in planning and implementing individual coordinator roles for patients with complex or long-term needs of care. I have also been in contact with national authorities around the introduction of these arrangements, e.g., through consultation responses and discussions as part of a national network. These various roles have given me the opportunity to take different perspectives on continuity of care. My experiences have also

contributed to the genuine curiosity that has inspired the research questions addressed in this thesis.

On the one hand, this poses a risk that my preconceptions would bias the interpretations. Aware of this challenge, I have actively used opportunities to challenge my views through discussions in courses and conferences. I have also had repeated negotiations of analyses and findings with the supervisors who have different backgrounds (medicine, psychology and health service research). On the other hand, I also regard my experience as a resource that was valuable in designing the research questions, the study aims, and in understanding the informants' responses during data collection.

I have kept a log throughout the process for each sub-study and the process as a whole. Regularly returning to the log has helped me to highlight the thoughts I have had and how they have changed. It also helped me maintain a reflective focus on the consequences of the choices I have made and my justifications for making those choices.

6.2 Choice of design

The thesis comprises studies of policy, practice and patient experiences concerning providing continuity of care for patients with complex or long-term healthcare needs. We considered it important to reflect the central parts of relevant policy initiatives, a broad variation of patients' needs, as well as diversity in hospital coordination practices. We, therefore, chose to study care coordination in hospitals (Paper I and II), as policy and practice, across patient groups and settings. Although the thesis has a hospital perspective, healthcare from the primary sector was included in the study of patient experiences (Paper III). Limiting the main focus of the thesis to one of the key actors in integrated care - clinical hospital units - enabled more in-depth insights into the realities of providing integrated care according to political ideals. This was considered crucial in light of an increasing number of patients with complex needs in combination with a reduction in patients' length of stay and increased efficiency requirements. More specific arguments for the design of the respective studies were as follows.

Studies of healthcare policy cover a range of approaches, perspectives and methods, and can be directed at analysing the proposals, arguments or actions of governments, or at evaluating processes, implementation or outcomes of the specific policy in focus (Coveney, 2010; Shaw, 2010). The focus in Paper I was on exploring how political claims could be understood, aiming at enhancing the understanding of challenges in the clinical contexts where this policy was to be implemented. Therefore, a discursive design was considered feasible and appropriate, allowing a critical reflection of the substantive content of these policy initiatives, as presented in policy documents (Bacchi, 2016; Hughes, G., 2017; Pereira, 2013; Shaw, 2010).

For new coordinator roles to be integrated into hospital practices, they must build on and complement existing organization and work methods, and preferably align with established coordination practices (Høyem, 2015; Krogstad et al., 2002; Olsvold, 2012). Thus, in Paper II our attention was directed towards hospital healthcare providers who took on a coordinator role, aiming to understand current coordination practice in contexts relevant for the implementation of the roles described in the policies. The coordination activities of interest in this study took place intermittently, in various wards or units within the hospitals, and for a wide range of the patients. Hence, semi-structured interviews with the health-care providers about their experiences were considered well suited for illuminating the research questions.

Person-centred integrated care (PC-IC) is identified as central in enhancing the quality of care (The National Institute for Health and Care Excellence (NICE), 2016; World Health Organization, 2016). However, it is argued that there is a persistent lack of evaluation of care coordination programmes (Goodwin, Sonola et al., 2013). Unclear conceptualizations of person-centred integrated care and lack of unified frameworks against which to evaluate the care are factors contributing to the lack of evaluation. (Hughes, J. C. et al., 2008; Uijen et al., 2012). Most evaluation instruments focus on care events, not the process. Although some qualitative studies focus on experiences of the pathway process as a whole (e.g., Bayliss et al., 2008; Gallacher et al., 2011), they do not relate the patient experiences of care to an ideal. Thus, in Paper III the focus was to operationalize the PC-IC ideal into a process framework. By conducting an iterative process of applying this framework to the experiences of patients' individual pathways, we enabled validation of the different stages in the process in light of research literature.

6.3 Analysis

Due to the aims and focus of each of the three studies, the thesis as a whole includes three different datasets, which are analysed with three different methods. While the policy study had a critical approach, the practice study had a descriptive aim, and the patient-experience study had a combined descriptive and evaluative aim. This influenced how they were analysed.

Nevertheless, there were some commonalities in how the practical work was done. In all studies, a group of researchers conducted the analyses. While I collected and prepared the data for analysis and conducted the primary analysis (I and II), the co-authors read the selected parts of the policy documents (I) and the interview transcripts (II). In study III, Gro Berntsen was the main analyst, while Deede Gammon and I participated actively in the Connect and the Troms-Ofoten populations, respectively. In all studies, the coding and analyses were negotiated between the authors, thus strengthening the validity of the interpretations.

One challenge throughout the analysis was the operationalization and use of concepts. To start with the conclusion; ‘continuity of care’ became the chosen overarching term, as mentioned in the background section. However, this concept was not sufficiently specific when formulating the research questions and aims for the study of policy, practice and patient experiences, respectively. Based on review of literature as presented in the background section; we chose ‘coherent care pathways’ to express continuity of care in policy (study I), ‘pathway coordination work’ to capture the activities/efforts in clinical practices aiming at continuity of care (study II), and ‘person-centred integrated care’ as the ideal against which to evaluate patient experienced quality of long-term care (study III). There were also translation issues that further complicated efforts to select, and consistently apply, the terms used in this thesis. In Norwegian, ‘pasientforløp’ is typically understood as a patient pathway or a patient trajectory, and as continuity of care. ‘Sammenhengende pasientforløp’ or ‘helhetlige forløp’ may be translated to (holistic) care pathways, continuity of care, integrated care pathways, integrated care, coordinated care, person-centred care, and other related concepts. Further; ‘behandlingslinje’ or ‘pakkeforløp’ has the English equivalents clinical pathway or critical pathway (Helsebiblioteket, 2015).

6.4 Transferability

In qualitative research, transferability refers to the extent to which findings can give meaning beyond the context in which the study was conducted (Malterud, 2001). Transferability has to do with the external validity of a study: For which other contexts may the results have relevance and be applicable (Malterud, 2013)? The sub-studies of policy, practice, and patient-experiences, aimed for knowledge enabling a more comprehensive understanding of the challenges in the day-to-day healthcare delivery regarding continuity of care. Insights into how health professionals in hospitals experience juggling between responsibilities towards policy, patient rights, professional values, and organizational constraints are likely to be relevant to diverse stakeholders and contexts.

In the trade-off between breadth and depth, this thesis reflects breadth at the expense of depth. Several coordination measures and coordinator roles are operative in hospital practices, as well as in primary care that may have implications for the aim, the infrastructure and the results of pathway coordination around patients with complex needs. Consequently, this thesis has investigated a limited selection of coordination initiatives, and are in danger of missing out important aspects. However, the data and informants cover a broad range, from different types of policy papers (Paper I), coordinators working at different departments at different hospitals throughout Norway (Paper II) and patients with different conditions and healthcare needs (Paper III). It seems thus fair to claim that although it is possible to study these questions in more depth, the choice of a broad approach has had valuable benefits.

7 Discussion of findings

After a summary of the findings, I will discuss how to define good (enough) quality regarding continuity of care. This is followed by a discussion of challenges in the practice of realizing continuity of care within local healthcare contexts, and a section on identifying the unique complexity of the individual patient and care context.

7.1 Summary of findings

The main contribution of this thesis are insights into continuity of care that are derived by studies of policy, practice and patient experiences in a healthcare delivery perspective focused on the implications for hospitals. The three papers explore continuity of care-initiatives for patients with long-term and complex healthcare needs across diagnoses and settings in hospitals as policy and practice, in addition to the testing and refinement of a framework for the evaluation of patient experienced continuity of care according to ideals of person-centred integrated care.

In study I, it was found that the Norwegian policy documents framed the challenges; lack of coherent care pathways and lack of stable and responsible professionals for patients with complex needs, as a responsibility issue. The prescribed solution is extended personal responsibility for clinicians in the role of individual patient coordinators. The targeted patient group represents a wide variety of complexity. Moreover, the policies do not provide guidance for how coordination shall take place in heterogeneous hospital settings or how to solve the challenges of variation in tasks and aims, staff, and organization.

In study II, experienced practitioners told how they ‘kept one step ahead’ by negotiating solutions in the local contexts to establish continuity of care for the patients they considered to be particularly in need. They developed personal and context-sensitive coordinator roles and solutions and adjusted their ambitions to what they considered doable considering their personal authority and accessible resources.

The informants with experience as patients reviewed care quality by how care supported, or threatened, their own long-term goals, study III. The goals were related either specifically to

their treatment, or they covered a wider scope of their life situation. Patient experiences showed mainly satisfactory episodic care. However, gaps in care became apparent when evaluated in light of a goal-oriented process framework for person-centred integrated care (PC-IC). The PC-IC framework exposed a lack of long-term care goals and care plans, as well as an absence of monitoring of care delivery.

7.2 The quality of continuity of care as process-oriented care delivery in care pathways

“Good, coherent patient pathways should increasingly become a common frame of reference for all stakeholders within the health and care services.” (Helse- og omsorgsdepartementet, 2009, p. 14).

This is a broad policy ideal, indicating integrated care within and across organizational units. Coherent patient pathways are conceptualized as individualized, continuous and holistic services planned and delivered as a process adapted to the individual patient, with the patient actively involved (paper I). However, the concept is used about a variety of models, processes and experiences related to process-oriented care delivery (Schrijvers et al., 2012), as shown and discussed in Paper I, II and III. This makes it difficult to arrive at common quality standards for continuity of care both in general and for hospitals. Thus, there are no common standards for what should be relevant indicators of quality, nor which quality level to aim at when working to realize the policy goal of coherent care pathways for patients.

Furthermore, what can appear as a pathway in retrospect, may not have been planned as such from the beginning (Allen, 2018b). Thus, if we want to study the quality of continuity of care, we need to clarify whether we are investigating the outcome of a particular pre-planned intervention, or if we are investigating how a trajectory has developed out of circumstances that lacked pre-planning (Biringir, Størkson, et al., 2017). The latter may imply how patients experience the healthcare’s adherence to policy ideals in general regarding person-centred, continuous and holistic services, with the process as the focus for evaluation, as was the case in paper III.

Thus, to start to look at quality, which is a multidimensional construct (Mainz, 2003), it is necessary to consider how continuity of care is operationalized. As presented in the background chapter of this thesis, this ranges from a standardized clinical pathway for a defined patient group or treatment procedure within a hospital clinic, to care processes that extend hospital treatment and cover primary healthcare and patients' coping with health issues in daily life (De Bleser, Depreitere et al., 2006; Schrijvers et al., 2012; Vanhaecht et al., 2010). Care pathways may also be differentiated according to the predictability of the care process and the agreement around treatment, into chain models, hub models and web models (Vanhaecht et al., 2010, outlined in chapter 2.1.4). Combinations of these types may be in use for different aspects or phases of care in the same trajectory (ibid.).

The next question becomes how quality is conceptualized within the different models, i.e. how are existing pathway models and measures reported and documented? Broadly speaking, this ranges from measures to assess effects of care programs on patient outcomes (Rotter et al., 2010), to indicators that are mandatory to report to health authorities when particular pathways are implemented (e.g. Helsedirektoratet, 2015a). Patient-reported experiences (Biringer, Hartveit et al., 2017; Kuluski, K. et al., 2013) or documentation of how healthcare practices are organized (Pless, Van Hootegem et al., 2018) are other types of quality indicators.

Examples from the Norwegian context illustrate this variation in quality conceptualizations:

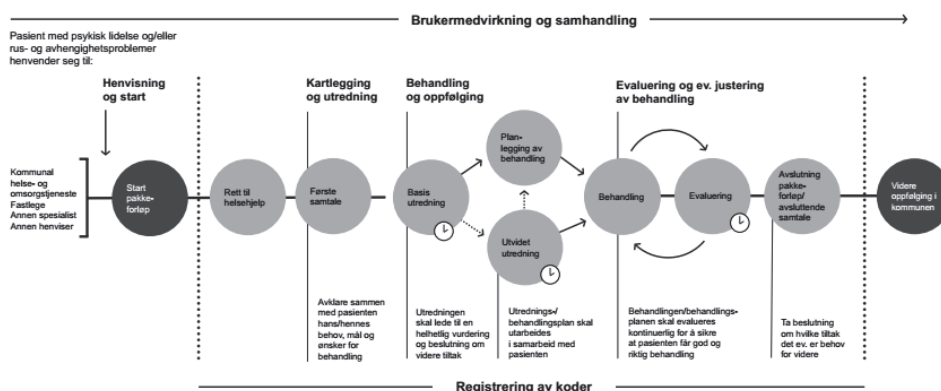
- In standardized pathways (e.g., for cancer, 2015a), quality is reported as the timely accomplishment of defined phases in pre-planned chains of care up to start of treatment, so that this may be evaluated in relation to the defined deadlines.
- In a recently implemented pathway model for mental healthcare and substance abuse treatment (Helsedirektoratet, 2018a, 2018b, 2018c), it is the completion of defined phases according to an ideal pathway process that is reported for each patient. This includes the following phases; referral and start of the pathway in specialized healthcare, assessment, treatment, evaluation, completion of specialized care, and plan for follow-up in primary care. (See the flowchart in fig. 5 below, and a larger version in the Appendix). It is also to be documented that each patient gets a required treatment plan covering all actions and including the planned points of evaluation.

- In the same pathway for mental healthcare and substance abuse treatment (ibid.), the patients are given the opportunity to systematically report their experience of treatment outcome and relation to the therapist. They can use digital response tools to give feedback after treatment sessions and how they experience treatment outcome throughout the care process.
- In integrated care pathways for hospital discharge and follow-up of frail elderly patients (Røsstad, 2016), quality is understood as adhering to deadlines and the use of checklists which are jointly created by professionals from specialized and primary healthcare.
- In specialized departments (e.g., rehabilitation units) with stable multidisciplinary teams and work practices customized to facilitate recovery trajectories, quality may be defined in terms of availability of structural resources.
- For patient care coordinator and contact physician roles in hospitals, with the individual responsibility of securing coherent care pathways for patients, quality is reported to the authorities in terms of as how many patients have been appointed a coordinator or contact physician.
- Regarding individual care plans (ICPs), it should be registered whether a patient is informed about ICP, if he wants an ICP and if a consent is signed, as well as if it is developed an ICP, and who is the coordinator (Helsedirektoratet, 2015b).

Figure 5. Illustration of the pathway model for mental healthcare and substance abuse treatment (Helsedirektoratet, 2018a, 2018b, 2018c) (See appendix for full size figure.)

Pakkeforløp for psykisk helse og rus

⌚ = Forlepstid



Another perspective on quality in terms of continuity of care is to look at how it is experienced by the individual patient over time (Haggerty et al., 2003). As presented above, quality is conceptualized in various ways in different pathway approaches. For evaluations to capture discontinuities or gaps in care, regardless of the patients' overall satisfaction with care (Biringier, Hartveit, et al., 2017), patients' experiences should be evaluated according to an operationalized set of values or process elements. In study III, the patients evaluated process quality, as experienced in their own individual pathway, in relation to operationalized ideals of continuity of care in terms of the PC-IC framework (Paper III). Their experiences of care quality were influenced by how care supported or threatened their own long-term goals. In line with what is shown by Bayliss et al. (2008) and Vermunt et al. (2017), they had individual expectations and goals for what to be included in the continuity of their pathway, varying from treatment goals as the cure of cancer to broader life goals.

Central to continuity of care, is the emphasis on securing patient-focused care (Vanhaecht et al., 2010). Thus, the patient voice and wishes are frequently and rightly presented as important in most models of care, with co-creation of care as a central value (Heaton et al., 2012). Hence, patient's wishes, including life goals, must be negotiated together with professionals in each service or unit to clarify the needed scope of continuity support in each case, as we have pointed out in the developed quality attributes of the PC-IC framework (Paper III). Together they must decide on which needs may be supported in the current healthcare context, and whether extended responsibility for coordination of pathways is better handled in another unit or sector.

The different conceptualizations of quality reviewed above can easily be positioned within the different quality dimensions by Donabedian (2005); structure, process, and outcome. Moreover, for the group of patients with complex needs who do not fit into the standardized clinical pathways, I find the process-dimension to be particularly central. The reason can be exemplified by the pathways for mental healthcare and substance abuse treatment under implementation in Norway (Helsedirektoratet, 2018a, 2018b, 2018c). In these pathways, all the quality dimensions described above are embedded. They are built around an ideal care process, which includes statutory documenting and reporting on completed process phases, as well as regular patient feedback, and with mandatory pathway coordinators on the system level with responsibility for the follow-up of several patients' pathways is (ibid.). All of these

quality aspects can be documented, without being compromised by the individually adjusted care trajectory.

7.3 Challenges in realizing continuity of care within clinical hospital practices

As described in Paper I, Norwegian legislation requires hospitals to appoint individual care coordinators to secure coherence in individual care pathways for patients with complex needs as well as being responsible for follow up and being available for the patient as a contact person. This implies assigning personal responsibility to professionals, mainly in clinical positions. The consequence, in most cases, is an expanded role and responsibility for the professional to ensure individualized care planning and pathway organized services across units, departments and sectors. For several of the clinician informants in study II, their actions and roles coincided to a large degree with those of the statutory patient care coordinators in hospitals. However, when asked, none of them saw themselves as performing the legislated care coordinator role. Thus, as pointed out several times in this thesis, designating individual clinicians in hospitals the responsibility of continuity of care is not a straightforward matter. Hence, there is still need for insights that can contribute to the design of workable and generalizable solutions.

Patients with complex needs receive specialized healthcare from departments that to varying degrees are staffed and organized to handle the individualized care planning and pathway coordination across units, institutions, and sectors that these patients are entitled to. Many of these patients require a tailored organization of healthcare services. This implies that the hospital needs to work across its organizational structures to deliver care adapted to the patient. To do so, they need to coordinate efforts across established chains of command - in essence creating a unique organization for each of these patients. The consequence is that those taking on coordinator roles need to both develop and manoeuvre within the emergent organization of regular hospital practices to create what may be called a virtual organizational solution for individual patients (Al-Salamah, Skilton et al., 2011). This organization does not exist for others than those involved in setting up the services to meet the demand for continuity of care. Vanhaecht et al. (2010, p. 119) give examples of ‘temporary teams’,

formed to meet individual patient needs, where the members are detached from their professional group or unit and assembled to solve defined tasks. Greenhalgh and Papoutsis (2018, p.2) point out the following about complexity of healthcare work, which I find relevant to illuminate this need of tailored solutions:

The gap between the evidence-based ideal and the political and material realities of the here-and-now may be wide. Decisions must be made on the basis of incomplete or contested data. People use their creativity and generate adaptive solutions that make sense locally. The articulations, workarounds and muddling-through that keep the show on the road are not footnotes in the story, but its central plot.

Allen has recently developed a conceptual framework for care trajectory management (2018b). The aim of this model, which is elaborated below, is to visualize the emergent organization of care trajectories in nursing practice. However, it is applicable also in a broader professional context (ibid.). This framework builds on insights from practice theory, where individual agency and structural conditions are understood as dynamic and mutually constitutive in accomplishing organizational phenomena through everyday actions (Aveling, Parker et al., 2016).

Facilitating pathway coordination requires personnel who take on the role of coordinators, either as legislated in Norway (Paper I) or as informal coordinator roles integral to their professional sense of responsibility (Paper II). Thus, care coordination is associated with extended roles (Bradway et al., 2012; Vuorinen et al., 2009), regardless of the mandate of such roles. Some even talk of ‘hybrid professionals’ (specialized nurses, extended scope therapists and others) that emerge as the result of extended responsibility in relation to coordination of care pathways (Pinder, Petchey et al., 2005). The coordination activities described by the majority of the interviewees in paper II were conducted as an extended clinical role, for which they assumed personal responsibility. Having the space and freedom – either formally or informally – to extend their roles in mobilizing the resources that they saw necessary for establishing continuity of care for patients in particular in need was highly valued.

Allen's framework provides an understanding and terminology that can help articulate the clinical practices involved in delivering continuity of care in hospitals. In short, the framework has three components:

1. trajectory awareness: maintaining an overview over evolving trajectories,
2. trajectory working knowledge: translational work securing the availability of the right information for the purposes at hand,
3. trajectory articulation: the practice of aligning trajectory elements in time and space.

The findings in Paper II resonate with these concepts in capturing central aspects of the described coordination work. The clinicians who took on a coordinator role manoeuvred in the systems through 'knowing the name of the game' by being sensitive and responsive in the interplay with other professionals and the patients to stay in front of things (trajectory awareness and trajectory articulation). They negotiated, defined and performed care coordination differently in different settings, going beyond formal coordination structures or organization (trajectory working knowledge). This is also in line with Doessing's (2018) description of how nurses activated informal coordination measures and created local solutions through 'rule-bending' when formal procedures were experienced as insufficient in inter-organizational coordination in complex pathways.

When viewing the expectations to the patient care coordinators in the policy documents (paper I) through the lens of Allen's (2018b) framework, the scope of the tasks becomes more visible. Primarily, the professionals must interpret the patient's needs in the individual situation and create an idea of a desired care pathway (trajectory awareness). Secondly, the professional in a coordinator role must locate and provide the needed resources to facilitate the process they see feasible (trajectory working knowledge). Thirdly, they must orchestrate the multidisciplinary work to align the needed knowledge, information, communication, mutual understanding and decision making to realize a pathway for the patient (trajectory articulation).

While standardized pathways, checklists, and protocols are used to help secure coordination of care, some elements of healthcare work resist efforts to rationalize and control, and depend on 'emergent organization' in terms of ongoing management and negotiations in response to exigencies (Allen, 2018b; Pinder et al., 2005). Hence, taking on the statutory coordinator role (Paper I) could expose one for being held accountable for tasks beyond one's control.

Moreover, this implies taking responsibility for fulfilling a legal obligation, which may come in conflict with the responsibility one has towards the daily work in the unit, to management and colleagues. Kjerholt, Wagner et al. (2013) found, in a Danish study, that nurses working with elderly patients with complex needs felt caught in a value conflict between providing continuity of care and adhering to the medical and episodic focus of the ward. Aveling et al. (2016) points out, in relation to patient safety work, a general challenge of healthcare as ‘the work of many hands’ which requires that the responsible professional knows the standards she is expected to meet, and has access to the needed resources, as well as the autonomy and capacity in the choice of actions.

As mentioned earlier, the Norwegian legislation present one central tool; the individual care plan (ICP) with the aim of securing a goal-directed, coordinated and individually adapted set of services across sectors and over time for patients with needs of coordinated services (Helsedirektoratet, 2015b) (described in section 2.2.2 in this thesis). It is the responsibility of the ICP-coordinator to ensure the process and follow-up. Individual care plans have not been implemented to the extent that was intended and anticipated (Bjerkan et al., 2011; Holum, 2013). Among explanations for why ICPs have not become the central tool that they were intended to, are: Lack of knowledge about ICP among the professionals (Sægrov, 2015), lack of capacity, training, infrastructure, and traditions for teamwork across boundaries (Alve, Madsen et al., 2013; Boge, 2017), lack of management priority and facilitation (Sægrov, 2015), lacking or inaccessible tools to facilitate the synchronous and non-synchronous update of the plan (Boge, 2017), as well as insecurity related to the responsibility and role of the ICP-coordinator (Alve et al., 2013; Holum, 2013). An overriding challenge in fulfilling this legislation is that it is not straightforward how to delimit what should be included in the ICP. As Sægrov (2015, p. 59) cites; ‘*Most of the care planning is taken care of outside the ICP.*’ Hansen (2007) points out that the idea of ICP builds on a rational-instrumental logic that does not correspond to the complex situations and contexts facing the users in need of such plans. Requirements to document patients’ needs and decisions regarding individual care plans in the patients’ EPR appears to enhance the use of the ICP procedures in hospitals. Nevertheless, this documentation is not to a sufficient degree followed up by management and authorities (Boge, 2017).

Although this thesis has not explicitly examined the individual care plan (ICP), it is relevant to revisit the research on ICP in light of the findings. Based on the broad approach to continuity of care in this thesis, it seems fair to suggest that the problem with developing individual care plans and realizing coherent care according to such a plan, relates to both factors in the patients' situations, to the ICP as a tool, and to factors in the healthcare institutions.

Firstly, unpredictability caused by complexity in health conditions and demanding life circumstances for patients in need of ICP limits healthcare's ability to plan and realize coherent care pathways according to plans. Holum (2013, p. 73) questions the suitability of IP for those who have complex and uncertain conditions and are in need of resource intensive support from several instances. Many of the patients in question arguably require the use of 'web models' (Vanhaecht et al., 2010, p. 119) where the measures are developed incrementally over time by temporary assembled teams, often across units and sectors. Secondly, the ICP is intended to be an overarching plan, thus assembling plans on more detailed levels e.g., a care plan, a treatment plan, and an education plan for the patient, ensuring an overview over aims and measures, as well as of the distribution of responsibility. As found in paper III, and argued in the discussion, an operationalization of the ideals of person-centred integrated care would benefit from following a dynamic cyclical goal-plan-delivery-evaluation process. Currently the ICP lacks the flexibility needed for orchestrating the many aspects, actors, goals and plans into facilitating a dynamic and incremental pathway process as intended. Thirdly, the ICP-coordination is to be conducted by clinicians in hospitals or primary care, taking on an extended responsibility as a coordinator. Medical or surgical diagnostics and treatment as well as short patient stays characterize many of these units in hospitals. Such hospital units are unlikely to have the time and resources to explicitly facilitate the capacity, competence, and organizational support needed for fulfilling the requirements of pathway coordination work. It is thus reasonable to conclude that until some form of 'over-institutional' structures and mandates can be activated to support such roles, it is unlikely that designating clinicians personal responsibility for individual care planning and delivery will suffice in orchestrating coherent care pathways for patients with complex needs.

In light of the previously described challenges, the legal basis for personal coordination responsibility and ICPs in fulfilling hospitals' contribution to continuity of care is dubious.

Building on the discussion above, I suggest re-examining the current emphasis on a cross-sectorial, long-term individual ‘master plan’ (ICP) as the main instrument for securing a coherent care pathway for patients with complex needs. Alternative infrastructures that foster coordination expertise and resources, and that enable individual and cyclical care processes that readily respond to emergent needs, insights and contexts are both needed and feasible. This infrastructure must comply with quality measures for ensuring both the structure, process and outcome dimensions of quality as discussed in section 7.2. Such a realignment of infrastructure entails a change from personal to systemic responsibility and will also require re-examining the legal dimensions of coordination policies which are, in any case, unclear.

This suggested infrastructure is largely reflected in the pathways for mental healthcare and substance abuse treatment that are currently being implemented in Norway (Helsedirektoratet, 2018a, 2018b, 2018c). These pathways build on ideal care processes and quality indicators that are defined as: completed phases of the process according to a flowchart, routine patient feedback (e.g., through electronic tools), and assigned pathway coordinators in designated positions, the latter of which I consider pivotal. Assembling coordination resources in dedicated positions may enable the coordinators to build relevant competence in coordination work on a system level, in addition to enabling capacity and stability of personnel during daytime and securing a clear mandate to act across units and sectors (Glogowska, Simmonds et al., 2015; Nutt & Hungerford, 2010). Furthermore, a clearer mandate due to the designated coordinator role may reduce the accountability conflict between realizing legalized assignments and adhering to the needs of the current hospital unit. Taken together, the task of facilitating individual pathway processes within such a structure is likely to be more manageable for a designated pathway coordinator than it is for a clinician to be accountable for an ‘overarching’ individual care plan. However, there is a trade-off between the benefits of centralized vs. decentralized coordination; i.e., whether the control over how tasks are aligned is integrated with, or separate from, the performance of these tasks (Pless et al., 2017). The next section examines the process of clarifying which solution is the most appropriate for each particular case.

7.4 Identifying the unique complexity of the individual patient and care context

Even if a process perspective as discussed above is implemented, the challenge of identifying which kind of pathway process model is feasible for each patient is still present. One obvious reason is the complexity inherent in adapting to individual needs. This is exemplified by Schaink et al. (2012) who states that the improvement of healthcare to patients with complex needs is hampered by a lack of common understanding of the multidimensionality of complexity, at the intersection between patient health conditions, personal situations, demographics, social circumstances, and physical environment (Fig. 1, p. 20).

In each of the three studies in the thesis, complexity is evident as a significant common dimension in creating continuity of care in various settings for patients with complex needs. In paper I, complexity is the central concept in the definition of the target groups for the studied patient care coordinators. Here, complexity is defined based on the number of services, units, and professionals involved for the patient in need of healthcare (Spesialisthelsetjenesteloven med kommentarer, 2013, p. 25). In paper II, the diversity of the interviewees' clinical work practices reflects complexity in that the continuity work emerged as context-sensitive. Study III demonstrates complexity in terms of care across healthcare levels and sectors, in addition to individual variations in patients' needs, expectations and goals that ranged from treatment goals to wider 'life goals'. In study II, we concluded that efforts to enhance continuity of care for patients with complex needs would benefit from a conceptual differentiation of coordination needs, aims, resources, and roles.

One way of making the types of issues that contribute to complexity more comprehensible in terms of the types of process and support needed, is to structure them according to the conceptual pair 'case complexity and care complexity'. These concepts are derived from de Jonge et al. (2006). Care complexity can be further divided into a professional and an organizational dimension as done by Doessing and Bureau (2015), entailing three complexity dimensions:

1. Case complexity: The characteristics of individual patients' resources, needs, and aims, as well as experiences, social relations and contextual factors.

2. Care complexity - the professional dimension. The requirements towards those who deliver and coordinate the care, including professional competence, resources, and roles.
3. Care complexity - the organizational dimension. The characteristics of the available organization and infrastructure of importance to continuity work in the relevant contexts.

These dimensions can be used to develop a system that identifies the unique complexity of the individual patient's situation in light of the current care context in order to identify the options and constraints in tailoring continuity of care to a given patient's needs.

The results of such assessment of complexity aspects may also be classified into low, medium or high in order to differentiate 'complexity profiles' that may support the operationalization of measures in different cases and contexts. The three-level grading structure is inspired by the integration framework of Leutz (1999, p. 86-87), where dimensions of patients' needs are graded in accordance with the degree of integration required to address the need.

Possible benefits of such a conceptual framework are; 1) a methodical and comprehensible identification of needs and resources, 2) a clarification of whether there is need to complement the available resources in the care context, as well as 3) arguments for the discussion of which type of pathway process and support that may be relevant in the individual case. A systematic assessment of the different complexity dimensions in each unique case may also be used to justify the required skill mix for care to individual patients with complex chronic conditions (Schaink et al., 2012).

An illustration of how such a framework might look is offered in table 3 below. The example within each of the complexity-dimensions and the descriptions of the three degrees of complexity, are derived from findings in the three papers and in dialogue with research literature. The relevant paper(s) and primary literature are referred to in the far right columns.

Table 3. Illustration of a possible framework to identify the unique complexity of the individual patient and care context.

Example of central aspects	Complexity dimension and degree of complexity			Paper	Reference
	Case complexity				
	Low	Medium	High		
Patient's capacity to participate	Good. Self-sufficient	Needs some support	Needs much support	III	(Myndigheten för vård- og omsorgsanalys, 2016)
	Care complexity - professional				
	Low	Medium	High		
Professional resources	Different professionals involved in care	Temporary team can be assembled	Focused multi-disciplinary team established	II	(Vanhaecht et al., 2010)
	Care complexity - organizational				
	Low	Medium	High		
Main context of collaboration	Within unit	Within institution	Within and across institutions	I, II, III	(Fineide & Ramsdal, 2014)

Other relevant aspects may expand each of the dimensions. For example the case complexity dimension may include the predictability of patient needs (multimorbidity, stability, urgency) (Bayliss et al., 2008; Vanhaecht et al., 2010), the degree of integration of services that is desired (linking, coordination, full integration) (Leutz, 1999), or the patient's desired scope of coordination (disease-specific treatment, all healthcare encounters or 'coping with life issues') (Doessing & Burau, 2015).

The professional dimension of care complexity may include the availability of relevant clinical guidelines, or if the situation is characterized by so high complexity that the

knowledge base is uncertain and controversial (Fineide & Ramsdal, 2014). Another aspect is the accessibility of multidisciplinary professional resources, and whether these are organized in temporary or permanent teams (Vanhaecht et al., 2010). Further, the question of available dedicated pathway coordinators with extended mandates, or capacity and competence in the clinical staff to take on extended coordinator roles, are central organizational resources.

In the organizational dimension of care complexity, some aspects of the work organization in the relevant unit may be e.g. mainly 'acute' care, mainly elective planned medical treatment, or team-based goal-directed work organization as in rehabilitation. Which ways of working are eligible in the given context; episodic, linear (chain model), multidisciplinary rehabilitation work (hub-model), or complex cyclical emerging (web-model) (Vanhaecht et al., 2010).

This system needs further development by adding relevant aspects for each of the three complexity dimensions together with stakeholders. The system can then be piloted in real-life settings and assessed in terms of how it supports the process of tailoring integrated care solutions for a diverse set of patients and contexts of care.

8 Conclusions

The overarching aim of this thesis was to investigate implications for hospital practices in realizing continuity of care for patients with complex or long-term needs, at the intersection between policy, practice, and patient experiences. The presented studies examined the obligations that Norwegian hospitals have to provide continuity of care in terms of individualized care pathways professionals' experiences of delivering healthcare in line with these obligations, and how patients experience continuity of care.

It was found that the Norwegian policies on coordinator roles in hospitals highlight ideals that resonate well with what patients want in terms of continuity of care. However, both patients with complex or long-term needs, as well as healthcare providers who took on coordination responsibilities in hospitals, experienced substantial challenges in realizing these ideals.

This thesis has identified three main obstacles to hospitals in their efforts to comply with the current policy legislation for coherent care pathways that entail designating personally responsible coordinators. These obstacles relate to:

1. the diversity and variation of complexity in the needs, aims and situations of the targeted patient group.
2. lack of infrastructure for providing individualized cross-sectorial coordination of services for patients in need of this, and thus also for the performance of the statutory coordinator roles.
3. unclear aims and quality requirements that undermine the documentation needed for monitoring hospitals' contribution to continuity of care for patients with complex or long-term needs, also undermining the attention needed from hospital management and authorities.

To ameliorate this situation, a systematic comprehensive identification of the unique complexity of the individual patient and care context is needed. Based on the findings of this thesis, and validated by research literature, a structure and some core elements as the start of a system for such assessment is suggested. Further developed into a framework, by adding validated aspects, this might be used to capture and express degrees and dimensions of complexity in patients' needs and resources, as well as of conditions of importance in the

relevant healthcare contexts. The aim is a more precise communication about which types of support are needed in cases where the needs cannot be met within the structures, routines, and resources available in the given healthcare units.

Many hospital units are not likely to have the time and resources to explicitly facilitate the capacity, competence, and organizational support needed for fulfilling the requirements of pathway coordination work. It is thus reasonable to conclude that until some form of ‘over-institutional’ structures and mandates can be activated to support such roles, it is unlikely that designating clinicians personal responsibility for individual care planning and delivery will suffice in orchestrating coherent care pathways for patients with complex needs..

It is therefore suggested that some structural requirements are needed to facilitate planning and customizing of individual pathways, particularly aimed at patients with complex needs. As presented above, a promising new approach is currently being implemented for patients under mental healthcare and substance abuse treatment in Norway. The pathway structures detailed in this approach allow for variation of needs and resources of patients and care contexts, and enable individualized planning and care delivery, while still securing that central requirements are covered. The required components of these pathways are a flow chart showing ideal pathway phases, mandatory documenting and reporting at designated points, systems for patient feedback during the process, and dedicated pathway coordinators on the system level. These pathway process infrastructures appear to be sufficiently stable to enable emergent and incremental work in alignment with the quality ideal for realizing continuity of care. Furthermore, when patients are admitted to such a complex pathway, authorities will receive mandatory documentation that processual requirements have been met. It is expected that such documentation could strengthen the patient rights as well as the accountability of the hospitals in relation to providing continuity of care for patients with complex or long-term needs that do not fit into other pathway structures.

Implications for clinical practice and research

This thesis provides arguments for routine assessments of the combination of patient needs and available contextual resources should be conducted in order to define which type of continuity measures that are best suited to solve the individual coordination needs (e.g.,

individual or system measures, chain, hub or web pathway models, mono- or interdisciplinary work). Additionally, this will provide knowledge about whether professional and/or organizational resources need to be supplemented. A preliminary system for supporting communication and negotiations surrounding such assessments has been proposed. While needing further development and validation, this system can potentially evolve into a common checklist for communication between patients and providers. The aim would be to support the process of pinpointing patient needs and resources in various clinical settings, operationalization of the pathway coordinators' role in individualized coordination, as well as decision of which type of pathway process and support that may be relevant in the individual case.

The recommended pathway infrastructures should be tested for patients with complex needs. Based on broadly defined ideal pathway phases, and the unique complexity of expected patient needs and involved healthcare contexts, different 'pathway profiles' could be drafted as frameworks for testing. Mandatory documenting and reporting on designated points, routine patient feedback during the process, and the experiences of dedicated pathway coordinators could contribute to new knowledge and possibly to further development.

Many hospitals have at their disposal various resources, operating in clinics and units, which are already involved in pathway coordination activities. Some examples of relevant roles and services are; diagnose-specific coordination nurses, discharge coordinators, dedicated pathway supervisors as those in the Coordinating Units, multidisciplinary ambulatory teams with different competence, etc. Organizing such resources into a formalized network so that they may be shared across units could give many benefits. Importantly, they could complement the available coordination resources in the different units, and be used to attain the types of support needed to meet the unique combinations of patient needs and contextual resources and constraints. Furthermore, this network could be an arena of support and access to coordination competence for clinicians taking on coordination tasks. It might also be set up as an ambulatory coordination support unit, as a measure to distribute professional resources that in any case will be used for complex or long-term pathway coordination.

Research and practices under the headings of 'chronic care' versus specialized rehabilitation have evolved somewhat separately, while commonalities between them are evident. The aims of coherent care pathways for patients with complex needs in the scope of individual life

goals and including multidisciplinary services across sectors, overlaps with how rehabilitation is defined. Integrated multidisciplinary rehabilitation units are a limited resource. Moreover, it appears that the way of working in these departments has constituted a model for achieving continuity of care through personally responsible coordinators, also where the coordinators do not have established multidisciplinary teams and ways of working accessible. Thus, based on what we found in study I and further discussed in section 7.3 in light of Allen's framework; the expectations to what clinicians in extended roles as patient care coordinators should achieve are wide and have much in common with the aims of rehabilitation. The aims and ideals, measures and structural resources for 'chronic care' versus specialized rehabilitation should be further explored in order to ensure the possibility of delineating which types of services are in demand in the particular case. This is needed to establish realistic expectations, to underpin sustainable service solutions, and as a basis for facilitating the necessary degree of structural requirements for the different solutions.

While study II showed how experienced professionals managed to negotiate continuity of care for some of their patients by 'knowing the name of the game, it is unlikely that taking on personal coordination responsibility for realizing coherent care pathways will be sustainable in many hospital practices. The obstacles hospitals face in securing coherent pathways for patients with complex needs by designating clinicians to take on a personal responsibility should be further explored. Among research questions raised during the course this thesis is how first-line clinical management perceive and deal with emergent trajectory work, as well as how they consider the expectations of extended responsibility for trajectory facilitation. Their roles are decisive in determining whether and how needs, capacity, competence, and infrastructure for emergent trajectory work is acknowledged and facilitated around patients who are not served by clinical pathways or other existing care organization. The Translational Mobilization Theory (TMT) (Allen, 2018a; Allen & May, 2017) represents a promising conceptual frame for in-depth case studies to explore the dynamic multifactorial challenge of realizing ideals of continuity of care.

9 References

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Paper I

Paper II

Paper III

Appendix

Paper I

Høyem, A., D. Gammon, G. R. Berntsen and A. Steinsbekk (2018):

Policies Make Coherent Care Pathways a Personal Responsibility for Clinicians: A Discourse Analysis of Policy Documents about Coordinators in Hospitals.

International Journal of Integrated Care 18(3): 5, 1-13.

Paper II

Høyem, A., D. Gammon, G. Berntsen and A. Steinsbekk (2018):

Keeping one step ahead: A qualitative study among Norwegian health-care providers in hospitals involved in care coordination for patients with complex needs.

International Journal of Care Coordination 21(1-2): 15-25.

Paper III

Berntsen, G., A. Høyem, I. Lettrem, C. Ruland, M. Rumpsfeld and D. Gammon (2018).
A person-centred integrated care quality framework, based on a qualitative study of patients' evaluation of care in light of chronic care ideals.
BMC Health Services Research 18(1).

Appendix

Interview guides

Study II. Interview guide

Study III. Interview guide Connect and Troms-Ofoten project

Information letters with consent form

Study II. Information letter with consent form

Study III. Information letter with consent form Troms-Ofoten project

Study III. Information letter with consent form Connect

Applications and approvals

Study II. Godkjenning Personvernombud UNN 09.02.15

Study II. Forlengelse Personvernombud UNN 09.01.18

Study III. Godkjenning REK Connect 12.04.11

Study III. Internforankring Connect OUS 04.04.11

Study III. Godkjenning Personvernombud Connect, UNN 06.05.11

Study III. Svar fra REK Troms-Ofoten prosjektet 09.11.2011

Study III. Godkjenning Personvernombud Troms-Ofoten prosjektet, UNN 16.11.11

Study III. Godkjenning forlengelse og slettetidspunkt. Personvernombud UNN, Troms-Ofoten prosjektet og Connect 20.03.18

Flowchart

Care pathway for patients in mental healthcare and substance abuse treatment

Interview guides

Study II. Interview guide

Study III. Interview guide Connect and Troms-Ofoten project

Interview guide – English translation

Study II. Keeping one step ahead

Background

This was a qualitative study with semi-structured individual (7), duo (1) and group interviews (2) with health-care providers in hospitals, involved in care coordination for patients with complex needs.

I made minor adjustments in the interview guide for each type of interview. Mainly this regarded the order of the questions, starting with what was most relevant for the role of the interviewee(s). For those who had dedicated coordinator roles, questions about their role was the first topic. For those in clinical positions, interviewed in groups, we started talking about the understanding of the aim of continuity of care for the patients and the coordination work.

The following questions guided all interviews

- What do you define as coordination work aiming at continuity of care for the patient?
- How do you perform this type of coordination work?
- How do you experience being a coordinator or taking on coordination responsibility?

Introduction

Short introduction about the research project, the informed consent and the rights for the participants. Practical information about the interview, such as timing and audio recording.

Opening

The participants were asked to give a short presentation of their working role and position, the unit they worked in and which patient groups they had within their responsibility.

In both the individual, duo- and group interviews the interviewee(s) were then asked to spend a few minutes to describe a patient they had met in their work, who they considered to be in need of support to experience continuity of care and overview over their healthcare services.

Topic 1. Continuity of care for the patient

The aim of the new coordinator role in hospitals is to enhance continuity, overview and predictability of healthcare and thereby increase patients' conditions for self-management of long term and complex conditions.

- What do you understand by the statement "a coherent and holistic care pathway for the patient"?
- What characterizes the patients who needs support to establish continuity and overview in their healthcare trajectory at the unit where you work?
- How do you understand the hospital's responsibility for continuity of the patients' care pathway?

Topic 2. Coordination and coordination work

- Out of what you do in your job, what will you describe as coordination or coordination work?
- What do you do when you are coordinating, in different phases of the patient's process, before/under/after hospital stays?
- What is included in your coordination work? Different professions, different units in the hospital, or units outside the hospital?
- How is coordination needs assessed for newly admitted patients?
- How do we know that we have succeeded with the coordination work?
- Do you experience challenges in coordination work? How do you understand these?
- Is it meaningful to talk about "continuity work"?
- What is central to succeed in coordination work?

Topic 3. Being a patient care coordinator or taking on coordination responsibility

- Have your hospital, or your department, implemented the new care coordinator scheme that is obligated as part of the Coordination reform?
- How do you understand being a care coordinator for an individual patient? If you have experience from such a role, what is your responsibility?
- How do you recognize that a patient needs a care coordinator?
- Which tools may be of use for a patient care coordinator?
- Do you use individual care plans, treatment plans or similar? How do you experience these plans and the use of them?
- What do you think about specialized healthcare's responsibility for coordination by the use of individual patient coordinators?

Closing questions

- Based on what we have discussed; what do you think is needed for patients with long-term complex needs to experience continuity of care?
- Is there anything that you think is important, related to the topics of this interview, that we have not mentioned, or that you think ought to be further elaborated?

Thank you so much for your time and contribution!

Interview Guide- English translation.

The individual Patient Pathway

The interviewer reviews the patient's medical history, as presented in the synopsis based on the electronic health records, together with the patient at the start of the interview.

An overview of your health service visits during this period

Are there any important healthcare events that are missing?

Is any of the information I have shown you wrong?

Do you want to add any visits to services outside the conventional health service that was important to you at in this period? Examples: dental services, physiotherapy, alternative therapy, etc.

Think of your overall care. How did you experience the collaboration with the health services during this period?

Key health service events in the review period

What events were important to you? Describe why they were important.

What events were particularly satisfactory - describe these and why they were satisfactory.

What events were particularly challenging - describe these and why they were challenging.

Did these events have consequences for you?

Goals and plan for treatment, and follow up of treatment over time

For long-term illness or conditions, it matters that both caregivers and patients have a common view on what the goals of care are and how care will be delivered.

What do you understand by the term “goals of care”?

The “goals of care” will depend on how your condition(s) effect(s) your life, what is realistic to achieve and what matters most to you in your life.

Are you able to formulate what you consider your goals of care the last year - can you explain why?

Have you and your providers discussed goals for your current/future care?

Choice of treatment

Have your providers told you or discussed with you whether there are different treatment options for your condition(s) that you may choose among?

To what extent do you feel that health professionals know your personal preferences when they choose or recommend a treatment?

To what extent do you feel health workers actively include your significant others in discussion/information when they choose or recommend a treatment?

In treatment of acute illness, health professionals often have to make quick decisions on your behalf. However, in long-term illnesses/conditions, it is useful to schedule follow up over time. Here we are referring to scheduling multiple contacts over time and perhaps also coordination across different parts of the health service that are responsible for different parts of the follow-up.

How do you understand the term follow-up?

Do you know if a follow-up plan has been made for you?

What do you think might be the potential benefits from a follow-up plan?

To what extent do you feel health professionals discuss with you and take into account your personal situation when they make a follow-up plan for you?

To what extent do you feel health professionals involve your significant others when they make a follow-up plan for you?

If there is no follow up plan, do you feel that health workers actively contact or summon you to discuss how things are progressing after a treatment has been recently started or ended?

Integration between services and transition between services

You have probably experienced being referred from one part of healthcare to another for assessment or treatment. Now we wish to focus on transitions between services in healthcare (e.g., from GP to hospital or from Department A to Department B). We want to look at the coherence of services, both concerning how they are organized, how information travels between the services and how your needs have been taken into account.

(Organizational continuity)

When you were referred to another unit in the health service, how was the decision made and how was it communicated to you?

Did the referral proceed as you had expected/or were explained?

If a referral did not proceed as it should, did this have any consequences for you?

(Informational Continuity)

Did you get the sense that the providers that you have met had the necessary knowledge of your medical history (previous test results, past decisions, etc.)?

If you experienced the provider was not entirely up to date on your history, did this have any consequences for you?

(Relational continuity)

Did you get the sense that the providers that you have met, from your point of view, have the necessary knowledge about you and your situation, to understand your ability to be actively involved in your treatment and to understand what was important to you in this situation?

Do you feel that health professionals ask you how the ongoing treatment fits your life situation and what matters to you?

If you experienced a lack of knowledge about you - did this have any consequences for you?

Self-care for your conditions

For most long-term conditions, there are some things you can do yourself to make it easier to live with the disease and to prevent complications or recurrence of the disease.

Do you feel that health professionals informed you about your self-management opportunities for well-being and prevention of exacerbations?

Have you been offered or received information/training to develop your self-management skills? For example; courses, information materials, referral to peer support groups, etc.

Did you receive too much/too little information/education? Was information provided when you needed it in a timely manner?

Do you feel that health professionals discuss with your significant others their opportunities to contribute so that you are all able to cope as well as possible with your condition?

Self-care - general health and wellness

Life with long-term conditions can present challenges in complying with general health and lifestyle advice.

Have you been offered or received information/education about what you can do to safeguard your general health in your current situation? For example, lifestyle, diet, physical activity, etc.

Do you feel that health professionals discuss with your significant others what you can do together to safeguard your general health in the current situation?

The vision for a course of treatment?

If you think back on your patient journey - and allow yourself some "hindsight" - how would you describe the ideal healthcare pathway for you? Please provide the reasoning behind your answer if you feel you can.

Finally - do you have any comments/questions to us who are doing this study?

Do you have anything you want us to convey to the hospital management?

Thank you for your help and best wishes to you!

Information letters with consent form

Study II. Information letter with consent form

Study III. Information letter with consent form Troms-Ofoten project

Study III. Information letter with consent form Connect

Forespørsel om deltakelse i forskningsstudie

Koordinering i spesialisthelsetjenesten omkring pasienter med langvarige og komplekse behov

Bakgrunn

Et økende antall pasienter har sammensatte tilstander og behov for kontakt med ulike deler av helsevesenet over tid. Mange opplever utfordringer med kontinuitet og sammenheng i helsetjenestene. Myndighetene har tatt initiativ til ulike tiltak for å øke kontinuitet, forutsigbarhet og muligheter for pasienters egenmestring av langvarige og sammensatte tilstander.

Blant annet er det etablert flere ulike koordinatorordninger: koordinator etter spesialisthelsetjenesteloven, individuell plan med koordinator, forløpskoordinator for kreft, og høsten 2014 ble forslag til ny ordning som kontaktelege lagt ut til høring. Andre koordineringsordninger eksisterer ved siden av disse. Flere fantes allerede før samhandlingsreformen – både internt i kommunen eller i sykehuset, og for å koordinere mellom tjenestene.

Til tross for at det er etablert mange koordinatorordninger, har vi begrenset kunnskap om hvordan koordinering omkring pasienter med sammensatte behov utføres i praksis i avdelinger og enheter. Vi vet også lite om hvilke utfordringer fagfolk erfarer i forbindelse med innføring av nye koordineringsordninger i eksisterende arbeidspraksiser.

Formål

Denne studiens formål er å utvide kunnskapen om hvordan fagfolk i spesialisthelsetjenesten fanger opp og forholder seg til pasienter som trenger bistand til kontinuitet og sammenheng i sine forløp, hvordan koordineringsarbeid utføres i praksis, og på hvilken måte nye koordineringsordninger eventuelt får sin plass.

Dybdekunnskap om hvordan det praktiske helsearbeidet organiseres og utføres, er sentralt når nye koordineringsordninger skal utvikles og innføres på en vellykket måte.

Hvem forespørres?

Dere som forespørres om å delta er fagfolk i spesialisthelsetjenesten som har bred erfaring fra pasientrettet arbeid som også inkluderer koordinering omkring pasienter med langvarige og komplekse tilstander. Det er koordinerende enhet eller annen instans ved helseforetaket som har formidlet denne forespørselen om deltakelse til personer de vurderer som aktuelle.

Hva innebærer deltakelse i studien?

Å være med i denne studien innebærer å delta i ett forskningsintervju som anslagsvis vil ta 1-2 timer i løpet av vinter/vår 2015. De fleste vil bli intervjuet i gruppe sammen med andre fagfolk. For noen kan det være aktuelt med individuelt intervju. Forskeren tar kontakt med de som har levert samtykkeskjema for å avtale tid og sted for intervjuet. Fortrinnsvis vil det gjennomføres på eller nær deltakerens arbeidsplass. Forskeren vil lede gruppeintervjuet, mens en medhjelper tar notater og kan bistå underveis. Det blir gjort lydopptak av alle intervjuene.

I forbindelse med gjennomføring av intervjuet vil deltakerne bli bedt om å fylle inn noe bakgrunnsinformasjon om utdanning og arbeidserfaring.

Eventuelle utgifter knyttet til transport, parkeringsutgifter og lignende blir dekket. Enkel servering kan påregnes. Dessverre har vi ikke mulighet til å dekke tapt arbeidsfortjeneste.

Hva skjer med informasjonen om de som deltar?

Alle personopplysninger vil bli behandlet konfidensielt. Navneliste og bakgrunnsinformasjon om den enkelte deltaker samt lydopptak fra intervjuene vil oppbevares på sikkert område på forskningsserveren i Universitetssykehuset Nord-Norges datasystem. Det er kun doktorgradsstudenten og en av veilederne som vil ha tilgang til personopplysninger og lydopptak.

Vi etterspør ingen sensitiv personinformasjon knyttet til områder som helse eller personlige forhold hos deltakerne. Det kan imidlertid aldri utelukkes helt at informasjon av sensitiv karakter kan framkomme i intervjusituasjoner. I forkant av gruppeintervjuene vil deltakerne bli bedt om å forholde seg til det som kommer fram i gruppediskusjonen som om det var taushetsbelagt.

Når lydopptakene skrives ut blir navnene byttet ut med fiktive navn, og eventuelle personlige kjennetegn fjernes. Avidentifiserte utskrifter fra intervjuene lagres på server ved Nasjonalt senter for samhandling og telemedisin ved Universitetssykehuset Nord-Norge, og vil kun være tilgjengelig for doktorgradsstudenten og veilederne. Det vil ikke være mulig å identifisere deltakerne i resultatene av studien når den publiseres.

Doktorgradsprosjektet som denne studien inngår i, skal etter planen avsluttes 1.4.2017. Lydopptak og personopplysninger slettes seinest 31.3.2025.

Studien er meldt til Personvernombudet for forskning ved Universitetssykehuset Nord-Norge (UNN). Det er UNN ved direktør Tor Ingebrigtsen som er databehandlingsansvarlig for prosjektet.

Frivillig deltakelse

Det er frivillig å delta i studien. Hvis du sier ja til å delta, har du rett til å få innsyn i hvilke opplysninger som er registrert om deg. Du har videre rett til å få korrigert eventuelle feil i de opplysningene vi har registrert. Om du bestemmer deg for å delta kan du når som helst trekke ditt samtykke uten å oppgi noen grunn, og uten at det vil få noen konsekvenser for deg. Dersom du trekker deg fra studien, kan du kreve å få slettet innsamlede opplysninger, med mindre opplysningene allerede er inngått i analyser eller brukt i vitenskapelige publikasjoner.

På neste side finner du samtykkeerklæringen som skal fylles ut og signeres dersom du ønsker å delta.

Mulige fordeler og ulemper

Fordelen med deltakelse er å kunne bidra til økt kunnskap som i neste omgang kan ha betydning for helsetjenestens praksis overfor pasienter med sammensatte behov. Ulempen begrenser seg til tidsbruken. Siden det ikke er forventet noen økt risiko for uheldige hendelser knyttet til deltakelse i studien, er deltakerne heller ikke særskilt forsikret.

Studiens finansiering og tilknytning

Denne forskningsstudien er finansiert av Helse Nord RHF og inngår i Audhild Høyem sitt doktorgradsprosjekt ved Nasjonalt senter for samhandling og telemedisin, Universitetssykehuset Nord-Norge.

I tillegg til denne studien med utgangspunkt i fagfolks praksis i spesialisthelsetjenesten, inngår det i doktorgradsprosjektet også en studie med pasientperspektiv på kontinuitet og koordinering, og en studie med fokus på bruk av et IT-verktøy for kommunikasjon, koordinering og egenmestring.

Spørsmål?

Dersom du har spørsmål, kan du ta kontakt med ph.d.-student Audhild Høyem, tlf: 905 47 197, audhild.hoyem@telemed.no, eller prosjektleder Deede Gammon tlf: 909 77 963. Dersom du ønsker tilsendt resultatene fra studien når de foreligger kan du krysse av for dette nedenfor.

Samtykke til deltakelse i studien

Jeg har mottatt informasjon om studien og samtykker til å delta i intervju

(Navn med blokkbokstaver)

(Underskrift, dato)

Kontaktinformasjon for avtale om tid og sted for intervju:

E-post		
Telefon		

(Kryss av dersom du foretrekker å bli kontaktet på en av måtene)

- Jeg samtykker til å bli kontaktet seinere for avklaringer eller tilleggsspørsmål
- Jeg er villig til å bli kontaktet seinere for å bistå med å finne aktuelle pasienter som kan forespørres om å delta i seinere delstudie med pasientperspektiv, dersom dette skulle bli aktuelt.
- Jeg ønsker å få tilsendt artikkel eller annen publisasjon som er basert på denne studien

Signert samtykke leveres til den du fikk forespørselen fra.

Deltakerne blir kontaktet når det er tilstrekkelig antall deltakere fra helseforetaket.

Du trenger bare levere dette arket med signaturen. Behold de to første sidene som din informasjon om prosjektet.



Balsfjord kommune

Forespørsel om deltakelse i forskningsprosjektet ”Connect 2.0: Elektronisk verktøy for samhandling”

Bakgrunn og hensikt

Dette er en forespørsel til deg om å delta i et forskningsprosjekt for å prøve ut en Internettbasert samhandlingstjeneste, Connect 2.0. Hensikten med prosjektet er å kartlegge utfordringer ifm samhandling mellom pasienter og helsepersonell og evaluere nytten av Connect 2.0. Pasienter som deltar i studien vil gjennom Connect 2.0 få tilgang til nettbaserte sykdomsmestringsressurser og få hjelp og støtte av helse- og omsorgspersonell uansett hvor i behandlingkjeden de befinner seg. Studien vil evaluere hvordan og hvor ofte tjenesten benyttes, samhandling og kontakt mellom pasienter og helsepersonell, og prosjektdeltakernes opplevelse og nytte av tjenesten.

Studien er et samarbeid mellom Balsfjord kommune, Universitetssykehuset i Nord Norge (UNN) og Oslo Universitetssykehus.

Hva innebærer studien?

Deltagelse i studien går over 6 måneder, og innebærer at du kan benytte deg av Connect 2.0 så mye du ønsker og få råd fra helsepersonell i denne perioden. Som bruker av tjenesten logger du deg på med BankID slik du logger deg på din nettbank. Dette vil du få nærmere forklaring på. All informasjon som utveksles er beskyttet gjennom strenge datatekniske sikkerhetstiltak. Informasjon som utveksles vil bli kryptert og liggende i et sikkert system ved Oslo Universitetssykehus HF.

Vi vil be deg fylle ut et spørreskjema ved oppstart som inneholder spørsmål om noen bakgrunnsopplysninger om deg og din diagnose, og dine erfaringer med internett. I tillegg vil du motta spørreskjema etter 6 måneders bruk som omhandler hvor nyttig og brukervennlig du opplever denne tjenesten. Du vil bli bedt om å returnere disse i en vedlagt ferdig frankert konvolutt.

Et mindre utvalg av pasienter vil bli bedt om å delta i en diskusjonsgruppe sammen med andre pasienter eller individuelt intervju, og det kan være at du er blant dem som vil bli spurt. Diskusjonsgruppen, som vil vare ca 2 timer, vil blant annet dreie seg om hvorvidt Connect 2.0 har møtt dine behov, samt din opplevelse av programmets nytte og brukervennlighet. Et individuelt intervju kan vare opp til en time. Om du ikke ønsker å delta i en slik diskusjonsgruppe eller individuelt intervju kan du likevel være med i studien.

I tillegg til data som samles inn gjennom spørreskjema og intervju ber vi om din tillatelse til å innhente følgende:

- Data for hvordan du benytter tjenestene (hva som benyttes, hvor ofte, hvor lenge, innhold i meldingene).
- Enkelte opplysninger om sykdom og behandling fra din journal.

Om du ikke ønsker å delta i denne studien, vil du motta vanlig behandling.

Mulige fordeler og ulemper

Studien medfører ingen kostnader for deg og det er ingen risiko forbundet med studien. Gjennom din deltakelse vil du bidra til viktig kunnskap om hvordan Connect 2.0 kan være et verktøy for bedre kommunikasjon og samhandling med helsepersonell.



Balsfjord kommune

Fordeler for deg vil være at du får mulighet til å benytte denne tjenesten til støtte ift med sykdom. Du kan stille spørsmål via sikker e-post og få råd og veiledning fra din fastlege, eller annet helsepersonell som deltar i din behandling. Å kunne stille spørsmål og få svar fra fagpersoner uansett hvor du oppholder deg, kan kanskje hjelpe deg å håndtere sykdommen og eventuelle komplikasjoner bedre når du er hjemme.

Det er få ulemper og ubehag knyttet til deltakelse i studien. Diskusjonsgruppen vil bli avholdt med pauser, slik at deltakerne ikke skal bli slitne.

Hva skjer med informasjonen om deg?

Informasjonen som registreres om deg skal kun brukes slik som beskrevet i hensikten med studien. Alle opplysningene vil bli behandlet uten navn og fødselsnummer eller andre direkte gjenkjennerende opplysninger. En kode (studie-ID) knytter deg til dine opplysninger gjennom en navneliste. Navnelisten er atskilt fra alle opplysninger vi samler om studiedeltakerne. Det er kun autorisert personell knyttet til prosjektet som har adgang til navnelisten og som kan finne tilbake til deg. Hvis det kommer frem noe i korrespondansen i Connect 2.0 som er viktig for din behandling, vil dette bli dokumentert i pasientjournalen.

All informasjon om deg vil slettes etter at studien er avsluttet, senest 31.12.2025. Det vil ikke være mulig å identifisere deg i resultatene av studien når disse publiseres. Studien er anbefalt av Regional Etisk Komité (REK) Sør-Øst og Personvernombudet ved Oslo Universitetssykehus HF.

Frivillig deltakelse

Det er frivillig å delta i studien. Du kan når som helst og uten å oppgi noen grunn trekke ditt samtykke til å delta i studien. Dette vil ikke få konsekvenser for din videre behandling. Dersom du ønsker å delta, undertegner du samtykkeerklæringen på siste side. Om du nå sier ja til å delta, kan du senere trekke deg fra studien uten at det påvirker din øvrige behandling. Du kan i så fall også be om at de opplysninger vi allerede har fått fra deg blir slettet.

Dersom du senere ønsker å trekke deg eller har spørsmål til studien, kan du kontakte Karin sykepleier Sørli, tlf 90 96 54 89 eller prosjektkoordinator Vibeke Almaas, tlf 23 07 54 56.



Balsfjord kommune

Bakgrunnsinformasjon om studien:

Mennesker med sykdom kan oppleve mange problemer og bekymringer. Når de er hjemme mellom eller etter behandling er det ofte begrenset tilgang til profesjonell hjelp. Internettbaserte tjenester har vist seg å være nyttige i forhold til å støtte pasienter til å mestre daglige utfordringer og behov. Hvis Connect 2.0 i denne studien viser at det er nyttig for deltakerne, vil det i framtiden være aktuelt å utvikle tilsvarende tjenester som kanskje kan bli en del av det ordinære tjenestetilbudet til flere pasientgrupper.

Kriterier for å delta i studien er at du er over 18 år, behersker norsk skriftlig og muntlig, har tilgang til internett og har bankID som påloggingsnøkkel.

Kapittel B - Personvern, økonomi og forsikring

Personvern

Data som vil bli registrert om deg den tiden du deltar i studien er:

- opplysninger innhentet gjennom spørreskjema, gruppe- eller individuelle intervjuer
- kommunikasjon med helsepersonell gjennom Connect 2.0
- bruk av Connect 2.0 (fra systemlogg)
- opplysninger om sykdom og behandling (fra pasientjournalen)

Kun navngitte medlemmer av forskningsteamet vil ha tilgang til dataene. Alle medlemmene av forskningsteamet har taushetsplikt. Oslo Universitetssykehus HF ved administrerende direktør, er databehandlingsansvarlig.

Retten til innsyn og sletting av opplysninger om deg

Hvis du sier ja til å delta i studien, har du rett til å få innsyn i hvilke opplysninger som er registrert om deg. Du har videre rett til å få korrigert eventuelle feil i de opplysningene vi har registrert. Dersom du trekker deg fra studien, kan du kreve å få slettet innsamlede opplysninger, med mindre opplysningene allerede er inngått i analyser eller brukt i vitenskapelige publikasjoner.

Økonomi og Norges forskningsråds rolle

Studien er finansiert gjennom forskningsmidler fra Norges forskningsråd. Det er ingen interessekonflikter å melde.

Forsikring

Du er forsikret på samme måte som ved ordinære opphold/konsultasjoner ved sykehuset.

Informasjon om utfallet av studien

Som deltaker i studien har du rett til å få informasjon om utfallet/resultatet av studien.



Balsfjord kommune

Samtykke til deltakelse i studien

Connect 2.0

For pasient:

Jeg er villig til å delta i studien:

(navn i blokkbokstaver)

(dato og signatur)

For prosjektmedarbeider:

Jeg bekrefter å ha gitt informasjon om studien

(dato, signatur, rolle i studien)

Forespørsel om deltakelse i forskningsprosjektet

Pasientforløp i Troms og Ofoten – Helhetlig helsetjeneste

Bakgrunn og hensikt

Dette er et spørsmål til deg om å delta i en forskningsstudie. Formålet er å kartlegge utvalgte pasienters opplevelse av helsetjenestens tilrettelegging av tilbudet til personer som har en langvarig og/ eller sammensatt tilstand. Denne studien er en del av en større kartlegging i forbindelse med innføring av samhandlingsreformen i Troms og Ofoten-regionen.

For pasienter foreslått av kommunehelsetjenesten:

Du er foreslått som deltaker i denne studien av helsearbeidere i din kommune. De mener at din historie kan være nyttig for å se på samhandling og samarbeid innen helsetjenesten. Vi er også opptatt av hvordan helsetjenesten samarbeider med deg som pasient.

For pasienter foreslått av pasientorganisasjon:

Du er foreslått som deltaker i denne studien av din pasientorganisasjon. De mener at din historie kan være nyttig for å se på samhandling og samarbeid innen helsetjenesten. Vi er også opptatt av hvordan helsetjenesten samarbeider med deg som pasient.

Hva innebærer studien?

Dersom du velger å delta i denne studien vil forskerne i prosjektet gå gjennom din pasientjournal på sykehuset, hos fastlegen og evt. hos pleie- og omsorgstjenesten dersom de er eller har vært inne i bildet. Ut fra dette vil forskerne oppsummere din sykehistorie det siste året.

Forskerne vil så gå gjennom sykehistorien med deg i et intervju.

Der vil du få spørsmål omkring:

- 1) Sykehistorien din: Er den er riktig framstilt?
- 2) Hva er de viktigste helse- og livshendelsene for deg det siste året?
- 3) Hvordan opplever du samhandling og samarbeid innen helsetjenesten?
- 4) Hvordan opplever du sammenheng og involvering i din kontakt med helsetjenesten?

Du vil også bli bedt om å svare på et kort spørreskjema.

Mulige fordeler og ulemper

Denne studien vil ikke medføre verken fordeler eller ulemper for deltakerne. Det du gir av informasjon til studien vil ikke være tilgjengelig for dine behandlere i helsetjenesten. Dette skal brukes i regionens arbeid for en bedre og mer sammenhengende helsetjeneste. Vi vil også oppsummere resultatene i en forskningsartikkel som publiseres i et internasjonalt tidsskrift. Det vil ikke være mulig å identifisere deg i resultatene av studien når disse publiseres. Evt. informasjon som kan bidra til at du gjenkjennes vil bli endret (endret navn til et alias, fiktivt bosted etc) slik at du ikke kan gjenkjennes gjennom din historie.

Hva skjer med informasjonen vi samler om deg?

Intervjuene og spørreskjemaene vil bli lagret elektronisk på en datamaskin ved Universitetssykehuset Nord-Norge. Der vil de lagres på en slik måte at de er beskyttet mot tap og mot innsyn fra uvedkommende. Kun tre prosjektmedarbeidere vil ha tilgang til dataene i analysefasen av studien. Når studien er over vil dine data bli slettet.

Informasjonen som registreres om deg skal kun brukes slik som beskrevet i hensikten med studien. Alle opplysningene vil bli behandlet uten navn og fødselsnummer eller andre direkte gjenkjenningse opplysninger. En kode knytter deg til dine opplysninger gjennom en navneliste. Det er kun autorisert personell knyttet til prosjektet som har adgang til navnelisten og som kan finne tilbake til deg.

Frivillig deltakelse

Det er frivillig å delta i studien. Dersom du ønsker å delta, undertegner du samtykkeerklæringen på siste side. Du kan når som helst og uten å oppgi noen grunn trekke ditt samtykke til å delta. Dette vil ikke få konsekvenser for din videre behandling.

Dersom du har spørsmål til studien kan du kontakte:

- Audhild Høyem, mobil telefon: 905 47 197/ e-post: audhild.hoyem@unn.no, Master i helsefag, prosjektmedarbeider.
- Gro Berntsen mobil telefon: 905 18 895/ e-post: Gro.berntsen@telemed.no, dr.med, prosjektleder og forsker ved Nasjonalt Senter for Samhandling og Telemedisin

Oppgi at det gjelder prosjektet "Pasientforløp i Troms-Ofoten".

Ytterligere informasjon om studien finnes i kapittel A – utdypende forklaring av hva studien innebærer.

Ytterligere informasjon om personvern, økonomi og forsikring finnes i kapittel B – Personvern, biobank, økonomi og forsikring.

Samtykkeerklæring følger etter kapittel B.

Kapittel A- utdypende forklaring av hva studien innebærer

Hvorfor ble akkurat du spurt om å delta?

Du som får spørsmål om å delta i denne studien har en langvarig tilstand som krever behandling fra flere deler av helsetjenesten. Du er enten valgt ut av helsearbeidere i din kommune eller av din pasientorganisasjon. Kriteriet for å bli spurt er at de som spør mener at din historie kan være nyttig for å belyse samhandlingsutfordringene i helsesektoren.

Bakgrunnsinformasjon om studien

Den norske samhandlingsreformen peker på ukoordinerte og usammenhengende pasientforløp som en av de fremste utfordringene i det norske helsevesenet, og etterlyser studier av "bedre pasientforløp". Pasienter med behov for komplekse langvarige helsetjenester vil som regel trenge omsorg og behandling fra en rekke forskjellige helseaktører. Hver helsearbeider vil yte et tilbud som er i tråd med den faglige spesialisering og avgrensing av ansvar og roller som kjennetegnes ved den enheten han/ hun jobber innenfor. Pasienten "reiser" mellom aktørene og er således den eneste som erfarer hvordan en slik kjede av helsetilbud oppleves. Helsearbeiderne jobber på hver sin "stasjon" og ser først og fremst hva som foregår der. Selv om helsearbeidere kan si noe om hvordan en tiltakskjede bør være så er det bare pasientene som kan si noe om hvordan kontinuiteten i helsetilbudet oppleves.

Til tross for at det fra mange hold er understreket at pasientforløpet må forbedres, så kjenner vi ikke til noen studier som systematisk kartlegger pasientforløpene til pasienter med langvarige og komplekse behov på tvers av helsetjenesten – inkludert både allmennlegetjenesten, pleie og omsorgstjenesten og spesialisthelsetjenesten. Det er derfor et stort behov for å frambringe beskrivelser av hvordan pasientforløp kan se ut.

Pasientforløpsbeskrivelser vil kunne brukes som et felles utgangspunkt for diskusjon og avklaring mellom helseenheter og pasienter for å diskutere hva som er bra og hva som kan bli bedre på tvers av store faglige, kulturelle og geografiske forskjeller i helsetjenesten.

Denne studien påvirker ikke din behandling

Din behandling og ditt forhold til helsetjenesten vil ikke bli påvirket av om du deltar i denne studien. Dine behandlere vil ikke ha tilgang til det du forteller oss. Du kan når som helst trekke deg fra studien.

Hva skjer når du har samtykket i delta?

Dersom du samtykker i å delta, så vil vi be om tilgang til din journal hos de enhetene i helsetjenesten som du mottar tjenester fra: fastlegetjenesten, pleie- og omsorgstjenesten og/ eller ditt lokalsykehus. Vi vil gå gjennom din sykehistorie, og kartlegge dine besøk i helsetjenesten. Din sykehistorie vil så danne grunnlag for en samtale/ intervju med deg hvor du blir bedt om å beskrive hvordan du har opplevd det å være syk, og hvordan du er blitt møtt av helsetjenesten underveis.

Du vil ikke ha verken fordeler eller ulemper av å delta i denne studien. Evt. kostnader for reise i tilknytning til intervju vil bli dekket av oss.

Kapittel B - Personvern, økonomi og forsikring

Personvern

Opplysninger som registreres om deg er: Alle dine kontakter med helsetjenesten det siste året. Vi vil registrere hvor du har vært, hvem du møtte og hva som skjedde slik dette står i din pasientjournal. I intervjuet med deg går vi gjennom det vi har registrert om deg og din kontakt med helsetjenesten, slik at du kan forklare, rette eventuelle feil og legge til informasjon som ikke står i journalen. Deretter vil

vi samtale med deg om det som gjelder din sykehistorie og din opplevelse av helsetjenesten gjennom det siste året. Alle som får innsyn i journalen din og/eller studie-intervjuet har taushetsplikt.

Det er bare tre forskere i prosjektet (Gro Berntsen, Audhild Høyem og Deede Gammon) som vil ha tilgang til materialet i studien. Universitetssykehuset i Nord Norge ved administrerende direktør er databehandlingsansvarlig.

Rett til innsyn og sletting av opplysninger om deg og sletting av prøver

Hvis du sier ja til å delta i studien, har du rett til å få innsyn i hvilke opplysninger som er registrert om deg. Du har videre rett til å få korrigert eventuelle feil i de opplysningene vi har registrert. Dersom du trekker deg fra studien, kan du kreve å få slettet innsamlede opplysninger, med mindre opplysningene allerede er inngått i analyser eller brukt i vitenskapelige publikasjoner.

Økonomi

Denne studien er finansiert av Helse Nord RHF. Helse Nord RHF har ingen rettigheter eller mulighet til å påvirke analysene og utfallet av studien.

Forsikring

Det er ikke forventet at deltakelse i denne studien medfører verken fordeler eller ulemper. Det er heller ikke forventet noen økt risiko for helseskade eller annen skade. Det er derfor ikke nødvendig med noen særskilt forsikring utover den beskyttelse som gjelder for alle norske pasienter gjennom pasientskadeloven.

Informasjon om utfallet av studien

Dersom du ønsker å bli informert om resultatene fra studien kan du oppgi din e-post adresse eller vanlige postadresse på spørreskjemaet som inngår i studien.

Samtykke til deltakelse i studien

Jeg er villig til å delta i studien

(Signert av prosjektdeltaker, dato)

Hvordan ønsker du å bli kontaktet av prosjektleder ? Sett kryss og oppgi kontaktinformasjon:

- Telefon på telefonnummer:.....
- E-post: Epostadresse:.....
- Vanlig post: Postadresse:.....

Din fastlege er: (Navn på lege og legekantor):

Dette skjemaet sendes i vedlagte svarkonvolutt til:

Gro Berntsen, PB 35, Universitetssykehuset Nord-Norge HF, 9038 Tromsø.

Applications and approvals

Study II. Godkjenning Personvernombud. Universitetssykehuset Nord-Norge 09.02.15

Study II. Forlengelse Personvernombud. Universitetssykehuset Nord-Norge 09.01.18

Study III. Godkjenning Regional komite for medisinsk og helsefaglig forskningsetikk, sør-øst B. Connect 12.04.11

Study III. Internforankring Oslo Universitetssykehus. Connect 04.04.11

Study III. Godkjenning Personvernombud Universitetssykehuset Nord-Norge.
Connect 06.05.11

Study III. Svar fra Regional komite for medisinsk og helsefaglig forskningsetikk sør-øst.
Troms-Ofoten prosjektet 09.11.2011

Study III. Godkjenning Personvernombud Universitetssykehuset Nord-Norge.
Troms-Ofoten prosjektet 16.11.11

Study III. Godkjenning forlengelse og slettetidspunkt. Personvernombud
Universitetssykehuset Nord-Norge. Troms-Ofoten prosjektet og Connect 20.03.18



Deede Gammon
Nasjonal senter for telemedisin
9038 Tromsø

Deres ref.:

Vår ref.:
2015/701

Saksbehandler/dir.tff.:
Per Norleif Bruvold, 77755855

Dato:
09.02.2015

ANBEFALING AV BEHANDLING AV PERSONOPPLYSNINGER

Viser til melding om behandling av personopplysninger, mottatt 09.01.2015.
Meldingen gjelder prosjektet/registeret:

Prosjekt nr: 0441

Koordinering i spesialisthelsetjenesten omkring pasienter med langvarige og komplekse behov.

Formål: Denne studiens formål er å øke kunnskapen om hvordan fagfolk i spesialisthelsetjenesten arbeider med koordinering og hvordan de forholder seg til pasientenes behov for kontinuitet og sammenheng.

Prosjektet defineres som en kvalitetsstudie hvor Universitetssykehuset Nord-Norge HF er behandlingsansvarlig. Prosjektet er en delstudie i et PhD-prosjekt som utføres av Audhild Høyem. Studien er kvalitativ og omfatter intervju med fagfolk i helsetjenesten, individuelt og i gruppe

Prosjekter innenfor medisinsk og helsefaglig forskning igangsatt etter 01.07.2009 skal forhåndgodkjennes av REK. REK godkjenner også fritak fra taushetsplikten samt opprettelse av biobank i henhold til den nye Helseforskningsloven. Personvernombudets (PVO) rolle er å ha oversikt over forskningsprosjekter samt se til at informasjonssikkerheten og personvernet blir ivaretatt. Helselovgivningen stiller krav til samtykke også for kvalitetsstudier, men dette kan fravikes etter gitte kriterier. PVO vil fremdeles godkjenne behandlings- og kvalitetsregistre.

PVO har vurdert prosjektet, og finner at behandlingen av personopplysningene vil være regulert av § 7-26 i Personopplysningsforskriften og hjemlet etter Helsepersonelloven § 26, j.fr Personopplysningsloven § 33, 4. avsnitt. Kvalitetsstudier skal fortrinnsvis innhente samtykke fra den registrerte, men kan fravikes når tungtveiende grunner vanskeliggjør/ikke er tilrådelig for en slik innhenting. Det innhentes samtykke fra intervju-objektene. Godkjennelse fra REK er ikke nødvendig.

PVOs anbefaling forutsetter at prosjektet gjennomføres i tråd med de opplysningene som er gitt i selve meldingen, i øvrig korrespondanse og samtaler samt i henhold til

Personopplysningsloven og Helseregisterloven med forskrifter. Videre forutsettes det at data anonymiseres etter prosjektavslutning ved at kodelista slettes, jfr. Pkt 8.6 i meldeskjemmet samt at tilgang til kodelista tillegges prosjektleder.

Det er opprettet et eget område (mappe) på <\\hn.helsenord.no\UNN-Avdelinger\felles.avd\forskning> (o:\) med navn **0441** hvor all data i forbindelse med prosjektet skal lagres. Tilgang til dette området er begrenset til kun Audhild Høyem og Gro Berntsen og den som prosjektleder eventuelt definerer.

I tillegg er det opprettet et område på <\\hn.helsenord.no\UNN-Avdelinger\felles.avd\forskning\key> med navn **0441N** hvor nøkkelfil skal oppbevares og som bare Audhild Høyem og Gro Berntsen har tilgang til.

PVO vil også kunne få tilgang til området, jfr pkt. 8.5 i meldeskjema.

Det gjøres oppmerksom på at det skal gis ny melding (remelding) dersom registeret ikke er slettet eller ikke ferdig innen 3 år og som ligger til grunn for PVOs anbefaling.

PVO gjør oppmerksom på at dersom registeret skal brukes til annet formål enn det som er nevnt i meldingen må det meldes særskilt i hvert enkelt tilfelle.

PVO ber om tilbakemelding når registret er slettet.

Med hjemmel etter Personopplysningslovens forskrift § 7-12 godkjenner PVO at behandlingen av personopplysningene kan settes i gang med de endringer som er nevnt i dette skriv.

Med vennlig hilsen

UNIVERSITETSSYKEHUSET NORD-NORGE HF

Per Bruvold
Sikkerhetssjef IKT/Personvernombud

Kopi: Senterleder Susann Bäckstrøm
Audhild Høyem

Fra: 'Personvernombudet@unn.no'

Sendt: tirsdag 9. januar 2018 14:33

Til: Audhild Høyem

Kopi: 'Deede Gammon [Ekstern] (deede.gammon@rr-research.no)' ; Gro Rosvold Berntsen

Emne: SV: Prosjekt nr: 0441. Koordinering i spesialisthelsetjenesten osv. Remelding - prosjekt ikke avsluttet 3 år etter godkjenning

Hei

Takk for oppdatering av status.

Forlengelse av prosjektet til utgangen av februar 2020 er registrert og herved godkjent.

Mvh. PVO-teamet v/

Eva Henriksen

Seniorrådgiver personvern og
informasjonssikkerhet

Tlf: +47 957 31 836

Universitetssykehuset Nord-Norge HF

Kvalitets- og utviklingsavdelingen

Fra: Audhild Høyem

Sendt: mandag 8. januar 2018 17:08

Til: 'Personvernombudet@unn.no'

Kopi: 'Deede Gammon [Ekstern] (deede.gammon@rr-research.no)' ; Gro Rosvold Berntsen

Emne: Prosjekt nr: 0441. Koordinering i spesialisthelsetjenesten osv. Remelding - prosjekt ikke avsluttet 3 år etter godkjenning

Remelding - prosjekt ikke avsluttet 3 år etter PVO-godkjenning

Prosjekt nr: 0441. Koordinering i spesialisthelsetjenesten omkring pasienter med langvarige og komplekse behov, godkjent 9.2.2015. Ref. 2015/701.

Prosjektet er definert som en kvalitetsstudie hvor Universitetssykehuset Nord-Norge HF er behandlingsansvarlig. Prosjektet er en delstudie i et PhD-prosjekt som utføres av Audhild Høyem. Studien er kvalitativ og omfatter intervju med fagfolk i helsetjenesten, individuelt og i gruppe.

I PVO-godkjenningen av 9.2.2015 informeres det om at «det skal gis ny melding (remelding) dersom registeret ikke er

slettet eller ikke ferdig innen 3 år og som ligger til grunn for PVOs anbefaling».

Prosjektet pågår. Artiklene er i review-prosesser og det er planlagt innlevering av phd-avhandling i august 2018.

Jeg ber om at PVO-godkjenningen forlenges for 2 år fram til februar 2020.

Vennlig hilsen

Audhild Høyem

Phd-student

Samhandlingsavdelinga, Kvalitets- og utviklingscenteret UNN

Tlf. 905 47 197



UNIVERSITETET I OSLO

DET MEDISINSKE FAKULTET

Forskningssjef Cornlia Ruland
Oslo universitetssykehus HF
Senter for Pasientmedvirkning og sykepleieforskning
Rikshospitalet
Postboks 4950 Nydalen
0424 Oslo

**Regional komité for medisinsk og helsefaglig
forskningsetikk sør-øst B (REK sør-øst B)**

Postboks 1130 Blindern
NO-0318 Oslo

Telefon: 22 84 55 17

Dato: 12.04.11

Deres ref.:

Vår ref.: 2010/3396

E-post: post@helseforskning.etikkom.no

Nettadresse: <http://helseforskning.etikkom.no>

2010/3396b Connect 2.0: Elektronisk verktøy for samhandling mellom pasient og helsepersonell i kommune- og spesialisthelsetjenesten

Vi viser til søknad om forhåndsgodkjenning av ovennevnte forskningsprosjekt. Søknaden ble behandlet av Regional komité for medisinsk og helsefaglig forskningsetikk, REK sør-øst B, i møte 16.03.2011.

Prosjektleder: Cornlia Ruland
Forskningsansvarlig: OUS ved øverste ledelse

Saksfremstilling

Målgruppen for undersøkelsen var pasienter med kroniske lidelser, uten at dette var nærmere definert. Prosjektleder ble av komiteen i forbindelse med behandling av søknaden, bedt om å definere dette. Videre ble hun oppfordret til å redegjøre nærmere for hvordan konfidensialiteten omkring pasientjournalene var tenkt å kunne ivaretas, om fordelingen av oppgavene mellom de forskjellige aktørene UNN, OUS og Balsfjord kommune, og endelig gi en begrunnelse for hvorfor sosioøkonomisk status var en nødvendig variabel. Prosjektleder har svart tilfredsstillende på komiteens merknader.

Vedtak

Komiteen godkjenner prosjektet slik det nå foreligger.

Komiteens avgjørelse var enstemmig.

Godkjenningen er gitt under forutsetning av at prosjektet gjennomføres slik det er beskrevet i søknaden, i endringssøknad og de bestemmelser som følger av helseforskningsloven med forskrifter.

Godkjenningen gjelder til 01.09.2014.

Dersom det skal gjøres endringer i prosjektet i forhold til de opplysninger som er gitt i søknaden, må prosjektleder sende endringsmelding til REK.

Forskningsprosjektets data skal oppbevares forsvarlig, se personopplysningsforskriften kapittel 2, og Helsedirektoratets veileder for «Personvern og informasjonssikkerhet i forskningsprosjekter innenfor helse- og omsorgssektoren». Personidentifiserbare data slettes straks det ikke lenger er behov for dem og senest ved prosjektets avslutning.

Prosjektet skal sende sluttmelding på eget skjema, senest et halvt år etter prosjektslutt jfr. helseforskningsloven § 12.

Vi ber om at alle henvendelser sendes inn via vår saksportal:
<http://helseforskning.etikkom.no> eller på e-post til post@helseforskning.etikkom.no.

Vennligst oppgi vårt referansenummer i korrespondansen.

Med vennlig hilsen,

Stein Opjordsmoen Ilnér (sign.)
Professor dr. med
Komitéleder

Katrine Ore
Komitésekretær/Rådgiver

Kopi:

- Oslo Universitetssykehus HF, Rikshospitalet, ved øverste ledelse,
oushfdlgodkjenning@ous-hf.no

MEDISINSK OG HELSEFAGLIG FORSKNING

INTERNKONTROLL OG FORANKRING AV FORSKNINGSANSVAR (OBLIGATORISK)

Til: Cornelia Ruland

Kopi: Vibeke Almaas

Fra: Stab forskning, innovasjon og utdanning

Dato: 4. april 2011

Offentlighet: Ikke unntatt offentlighet

Sak: Internregistrering OUS vedr. forskningsprosjekt

Saksnummer ePhorte: 2011/2810

Forskningsprosjektet:

”Connect 2.0: Elektronisk verktøy Samhandling mellom pasient og helsepersonell i kommune- og spesialisthelsetjenesten. Flexible collaborative networks and patient provider partnerships in health care: critical factors”

Viser til innsendt søknad om igangsetting av forskningsprosjekt ved Oslo universitetssykehus. Det følgende er den formelle interne forankringen av søknaden.

- Stab forskning, innovasjon og utdanning sikrer internkontrollen og ivaretar nødvendig forankring av foretakets forskningsansvar.

Oppfylging av følgende forutsetninger ligger til grunn for den interne forankringen av studien:

Seksjon for personvern og informasjonssikkerhet har vurdert studien og har følgende forutsetninger til den planlagte databehandlingen av personopplysninger/helseopplysninger:

1. Behandling av personopplysningene / helseopplysninger i studien skjer i samsvar med og innenfor det formål som er oppgitt i meldingen.
2. Vedlagte informasjonsskriv med endringer benyttes.
3. Data lagres som oppgitt i meldingen. Kryssliste som kobler aidentifiserte data med personopplysninger lagres som angitt i meldingen.
4. Data slettes eller anonymiseres senest 31.12.25 ved at krysslisten slettes og eventuelle andre identifikasjonsmuligheter i databasen fjernes.
5. Dersom formålet, utvalget av inkluderte eller databehandlingen endres, må personvernombudet ges forhåndsinformasjon om dette.

Seksjon for biobank og registerstøtte har vurdert studien til ikke å være relevant i forhold til opprettelse av forskningsbiobank.

Enhet for klinisk forskningsstøtte/GCP har vurdert studien til ikke å være klinisk utprøving av legemidler til mennesker.

Studien må vurderes og godkjennes av Regional komité for medisinsk og helsefaglig forskningsetikk (REK), og eventuelle merknader må følges. Denne søknaden sendes inn via SPREK-portalen til REK. Det må være samsvar mellom navn på søker/prosjektleder i den interne forankringen og i den eksterne søknaden til REK.

REKs godkjenning sendes i retur til: oushfpbsentralgod@ous-hf.no

Ved samarbeid med eksternt forskningsinstitusjon, må

Seksjon for forskningsadministrasjon kontaktes, e-post: geir.gogstad@ous-hf.no

Ved inngåelse av kontrakt med eksternt industriell enhet må Inven2 (tidligere Medinnova) kontaktes, e-post: post@inven2.com

Studien er registrert i sykehusets offentlig tilgjengelig database over forsknings- og kvalitetsstudier (ForPro).

Lykke til med studien!

Med vennlig hilsen

Mette B. Stinessen
Seniorrådgiver

Stab forskning, innovasjon og utdanning
Oslo universitetssykehus HF

Vedlegg.



Gro Berntsen
Nasjonal Senter for Telsmedisin
9038 Tromsø

Deres ref.:

Vår ref.:
2011/1157

Saksbehandler/dir.tff.:
Per Norleif Bruvold, 77755855

Dato:
06.05.2011

ANBEFALING AV BEHANDLING AV PERSONOPPLYSNINGER

Viser til melding om behandling av personopplysninger, mottatt 15.04.2011.
Meldingen gjelder prosjektet/registeret:

0233 Connect 2.0

Formål: Hensikten med prosjektet er å kartlegge utfordringer ifm samhandling mellom pasienter og helsepersonell og evaluere nytten av Connect 2.0. Deltakere i studien vil gjennom Connect 2.0 få tilgang til nettbasert støtte til å håndtere sin sykdom, holde seg ”friskere”, og forebygge komplikasjoner. De kan følge med på egne symptomer og plager, få kunnskapsbaserte råd, kan utveksle erfaringer med andre pasienter i samme situasjon og stille spørsmål til helsepersonell uansett hvor de får behandling, i hjemmekommunen eller hos spesialist.

I denne studien ønsker vi å lære mer om samhandling og kontakt mellom pasienter og helsepersonell i primær- og spesialisthelsetjenesten, hvordan dette kan forbedres gjennom nettstøttet samhandling ved hjelp av Connect 2.0, nytten av verktøyet for pasienter og helsepersonell, og hvordan og hvor mye Connect 2.0 benyttes.

Prosjektet er en forskningsstudie som inngår i en multisenterstudie hvor Universitetssykehuset Nord-Norge HF er behandlingsansvarlig for den del av registeret som lagres lokalt. Forskningsansvarlig institusjon for hele studien er Oslo Universitetssykehus.

Forskningsprosjekter igangsatt etter 01.07.2009 skal forhåndgodkjennes av REK. REK godkjenner også fritak fra taushetsplikten samt opprettelse av biobank i henhold til den nye Helseforskningsloven. Personvernombudets (PVO) rolle er å ha oversikt over forskningsprosjekter samt se til at informasjonsikkerheten og personvernet blir ivarettatt. PVO vil fremdeles godkjenne behandlings- og kvalitetsregistre.

REK har godkjent prosjektet hjemlet etter Helseforskningsloven (HFL) § 10, se REK sak 2010/3396-6.

PVO har på bakgrunn av REKs godkjenning og tilsendte meldeskjema med vedlegg registrert prosjektet og opprettet et eget område (mappe) på [\\asterix7\felles.avd\forskning](#) (o:\) med navn 0233 hvor all data i forbindelse med UNNs del av prosjektet skal lagres. Tilgang til dette området er begrenset til kun prosjektleder og den som prosjektleder definerer. PVO vil også kunne få tilgang til området.

Det gjøres oppmerksom på at det skal gis ny melding (remelding) dersom registeret ikke er slettet eller ikke ferdig innen 3 år og som ligger til grunn for PVOs anbefaling.

PVO gjør oppmerksom på at dersom registeret skal brukes til annet formål enn det som er nevnt i meldingen må det meldes særskilt i hvert enkelt tilfelle.

PVO ber om tilbakemelding når registret er slettet.

Med hjemmel etter Personopplysningslovens forskrift § 7-12 godkjenner PVO at behandlingen av personopplysningene kan settes i gang med de endringer som er nevnt i dette skriv.

Med vennlig hilsen

UNIVERSITETSSYKEHUSET NORD-NORGE HF

Per Bruvold
Sikkerhetssjef IT/Personvernombud

Kopi: Senterleder Bjørn Engum

Region:	Saksbehandler:	Telefon:	Vår dato:	Vår referanse:
REK sør-øst	Gjøril Bergva	22845529	09.11.2011	2011/1913
			Deres dato:	Deres referanse:
			27.09.2011	

Vår referanse må oppgis ved alle henvendelser

Gro K Rosvold Berntsen
NST
Universitetssykehuset Nord-Norge
9038 Tromsø

2011/1913 C Pasientforløp hos personer med langvarig og sammensatte behov for helsetjenester

Vi viser til søknad om forhåndsgodkjenning av ovennevnte forskningsprosjekt. Søknaden ble behandlet av Regional komité for medisinsk og helsefaglig forskningsetikk i møtet 20.10.2011.

Forskningsansvarlig: Universitetssykehuset Nord-Norge
Prosjektleder: Gro K Rosvold Berntsen

Prosjektomtale (revidert av REK):

Den norske samhandlingsreformen peker på ukoordinert og fragmentert pasientforløp som en av de fremste utfordringene i det norske helsevesen, og etterlyser studier av "bedre pasientforløp". Til tross for stadig mer oppmerksomhet rundt dette begrepet, så er det lite systematisk forskning på hvordan slike forløp ser ut, eller hva som utgjør et godt eller dårlig forløp. Pasienter "reiser" mellom aktørene i helsetjenesten og er således den eneste som erfarer hvordan en kjede av helsetilbud eller et pasientforløp oppleves. Helsearbeiderne jobber på hver sin "stasjon" og ser først og fremst hva som foregår lokalt. Formålet med prosjektet er å ta utgangspunkt i pasientenes opplevelse og belyse pasientforløpene i forhold til kvalitet på tjenestene, kontinuitet og samhandlingsutfordringer. Prosjektet gjennomføres som en dybdestudie med både kvantitative og kvalitative metoder av forløpene til 8 pasienter med sammensatte og langvarige behov for helsetjenester.

Komiteens vurdering

Det oppgis i søknaden at hensikten med prosjektet er å belyse pasientforløp i forhold til kvalitet på tjenestene, kontinuitet og samhandlingsutfordringer. Dette skal undersøkes ved å ta utgangspunkt i pasientenes opplevelser. Komiteen oppfatter det slik at prosjektet kan gi kunnskap om helsetjenesten, men at prosjektet ikke vil gi kunnskap om helse og sykdom i seg selv. Bruk av helseopplysninger i prosjektet er ikke nok til at det faller innenfor helseforskningsloven.

Vedtak

Etter søknaden fremstår prosjektet som helsetjenesteforskning, og faller derfor utenfor komiteens mandat, jf. helseforskningslovens § 2. Prosjektet er ikke fremleggelsespliktig, jf. helseforskningsloven § 10.

REK antar for øvrig at prosjektet kommer inn under de interne regler som gjelder ved forskningsansvarlig virksomhet. Søker bør derfor ta kontakt med enten forskerstøtteavdeling eller personvernombud for å avklare hvilke retningslinjer som er gjeldende.

Komiteens avgjørelse var enstemmig.

Komiteens vedtak kan påklages til Den nasjonale forskningsetiske komité for medisin og helsefag, jfr.

helseforskningsloven § 10, 3 ledd og forvaltningsloven § 28. En eventuell klage sendes til REK sør-øst. Klagefristen er tre uker fra mottak av dette brevet, jfr. forvaltningsloven § 29.

Vi ber om at alle henvendelser sendes inn via vår saksportal: <http://helseforskning.etikkom.no> eller på e-post til: post@helseforskning.etikkom.no.

Vennligst oppgi vårt referansenummer i korrespondansen.

Med vennlig hilsen,

Arvid Heiberg
professor dr. med.
leder REK Sør-Øst C

Gjøril Bergva
rådgiver

Kopi til: bjorn.engum@telemed.no
post@unn.no



Gro K R Berntsen
Nasjonal senter for telemedisin
9038 Tromsø

Deres ref.:

Vår ref.:
2011/4292

Saksbehandler/dir.tff.:
Per Norleif Bruvold, 77755855

Dato:
16.11 2011

ANBEFALING AV BEHANDLING AV PERSONOPPLYSNINGER

Viser til melding om behandling av personopplysninger, mottatt 11.11 2011
Meldingen gjelder prosjektet/registeret:

0258 Pasientforløp hos pasienter med kroniske tilstander.

Formål: Vi ønsker å belyse samhandlingsutfordringene for pasienter med sammensatte og langvarige behov gjennom kvalitative dybdestudier av til sammen 8 pasientforløp som representerer gode eller utfordrende paseintforløp, slik pasientene selv har opplevd helsetjenestereisen.

Prosjektet er en forskningsstudie hvor Universitetssykehuset Nord-Norge HF er behandlingsansvarlig.

Prosjekter innenfor medisinsk og helsefaglig forskning igangsatt etter 01.07.2009 skal forhåndgodkjennes av REK. REK godkjenner også fritak fra taushetsplikten samt opprettelse av biobank i henhold til den nye Helseforskningsloven. Personvernombudets (PVO) rolle er å ha oversikt over forskningsprosjekter samt se til at informasjonssikkerheten og personvernet blir ivaretatt. Helselovgivningen stiller krav til samtykke også for kvalitetsstudier, men dette kan fravikes etter gitte kriterier. PVO vil fremdeles godkjenne behandlings- og kvalitetsregistre.

PVO har vurdert prosjektet, og finner at behandlingen av personopplysningene ikke faller inn under medisinsk- og helsefaglig forskning etter Helseforskningsloven. Prosjektet er ikke fremleggingspliktig til REK.

Behandlingen vil være regulert av § 7-26 i Personopplysningsforskriften og hjemlet etter Helseregisterloven § 5, j.fr Personopplysningsloven § 33, 4. avsnitt.

PVOs anbefaling forutsetter at prosjektet gjennomføres i tråd med de opplysningene som er gitt i selve meldingen, i øvrig korrespondanse og samtaler samt i henhold til Personopplysningsloven og Helseregisterloven med forskrifter. Videre forutsettes det at data slette etter prosjektavslutning, jfr. Pkt 6 i meldeskjemaet samt at tilgang til kodelista tillegges prosjektleder. Kodelista oppbevares adskilt fra forskningsdata hvor tilgang sikres.

Det er opprettet et eget område (mappe) på [\asterix7\felles.avd\forskning](#) (o:\) med navn 0258 hvor all data i forbindelse med prosjektet skal lagres. Tilgang til dette området er begrenset til kun prosjektleder og den som prosjektleder definerer. PVO vil også kunne få tilgang til området, jfr pkt. 8.5 i meldeskjema.

Det gjøres oppmerksom på at det skal gis ny melding (remelding) dersom registeret ikke er slettet eller ikke ferdig innen 3 år og som ligger til grunn for PVOs anbefaling.

PVO gjør oppmerksom på at dersom registeret skal brukes til annet formål enn det som er nevnt i meldingen må det meldes særskilt i hvert enkelt tilfelle.

PVO ber om tilbakemelding når registret er slettet.

Med hjemmel etter Personopplysningslovens forskrift § 7-12 godkjenner PVO at behandlingen av personopplysningene kan settes i gang med de endringer som er nevnt i dette skriv.

Med vennlig hilsen

UNIVERSITETSSYKEHUSET NORD-NORGE HF

Per Bruvold
Sikkerhetssjef IKT/Personvernombud

Kopi: Senterleder Bjørn Engum

Fra: "Personvernombudet, UNN" <Personvernombudet@unn.no>

Dato: tirsdag 20. mars 2018 13.20

Til: Gro Rosvold Berntsen <Gro.Rosvold.Berntsen@ehealthresearch.no>

Emne: SV: Status prosjekter registrert hos PVO ?

Hei Gro

Jeg setter status på de to prosjektene som «Avsluttet», men det betyr ikke at dataområdet blir slettet.

Det er registrert eget slettetidspunkt for det første prosjektet:

- Prosj. 0233 – Connect 2.0 – **sletting: 31.12.2025**

Det andre prosjektet har registrert slettetidspunkt lik sluttidspunkt (1.12.2015).

Men jeg oppdaterer og legger inn 5 år fra sluttidspunktet, altså:

- Prosj. 0258 – Pasientforløp hos pasienter med kroniske tilstander – **sletting: 1.12.2020**

Mvh. PVO-teamet v/

Eva Henriksen

Seniorrådgiver personvern og
informasjonssikkerhet

Tlf: +47 957 31 836

Universitetssykehuset Nord-Norge HF

Kvalitets- og utviklingsavdelingen

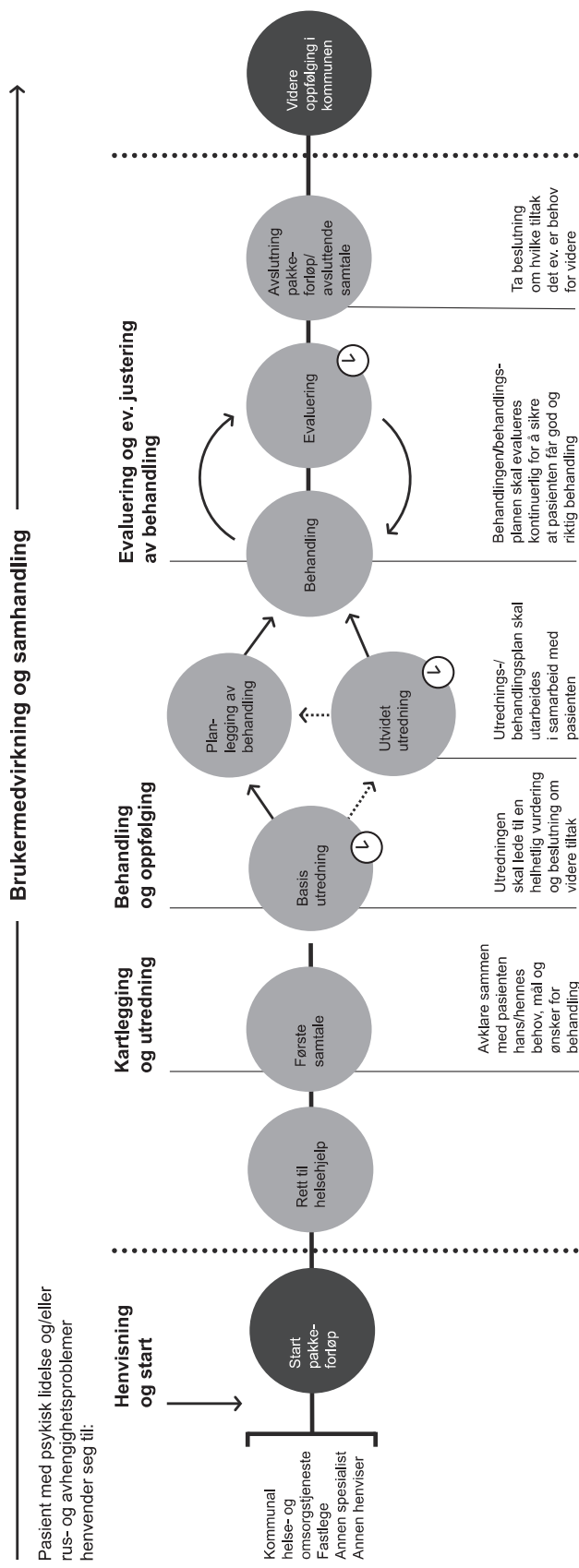
Flowchart

Care pathway for patients in mental healthcare and substance abuse treatment

Helsedirektoratet. (2018a). Pakkeforløp for tverrfaglig spesialisert rusbehandling. [Pathway for multidisciplinary specialized treatment for substance abuse]. (IS-2639). Oslo, Norway.

Pakkeforløp for psykisk helse og rus

⌚ = Forløpstid



Registrering av koder

ISM SKRIFTSERIE - FØR UTGITT:

1. Bidrag til belysning av medisinske og sosiale forhold i Finnmark fylke, med særlig vekt på forholdene blant finskattede i Sør-Varanger kommune.
Av Anders Forsdahl, 1976. (nytt opplag 1990)
2. Sunnhetstilstanden, hygieniske og sosiale forhold i Sør-Varanger kommune 1869-1975 belyst ved medisinalberetningene.
Av Anders Forsdahl, 1977.
3. Hjerte-karundersøkelsen i Finnmark - et eksempel på en populasjonsundersøkelse rettet mot cardiovasculære sykdommer. Beskrivelse og analyse av etterundersøkelsesgruppen.
Av Jan-Ivar Kvamme og Trond Haider, 1979.
4. D. The Tromsø Heart Study: Population studies of coronary risk factors with special emphasis on high density lipoprotein and the family occurrence of myocardial infarction.
Av Olav Helge Førde og Dag Steinar Thelle, 1979.
5. D. Reformer i distriktshelsetjenesten III: Hypertensjon i distriktshelsetjenesten.
Av Jan-Ivar Kvamme, 1980.
6. Til professor Knut Westlund på hans 60-års dag, 1983.
- 7.* Blodtrykksovervåkning og blodtrykksmåling.
Av Jan-Ivar Kvamme, Bernt Nesje og Anders Forsdahl, 1983.
- 8.* Merkesteiner i norsk medisin reist av allmennpraktikere - og enkelte utdrag av medisinalberetninger av kulturhistorisk verdi.
Av Anders Forsdahl, 1984.
9. "Balsfjordsystemet." EDB-basert journal, arkiv og statistikkssystem for primærhelsetjenesten.
Av Toralf Hasvold, 1984.
10. D. Tvunget psykisk helsevern i Norge. Rettsikkerheten ved slikt helsevern med særlig vurdering av kontrollkommisjonsordningen.
Av Georg Høyer, 1986.

11. D. The use of self-administered questionnaires about food habits. Relationships with risk factors for coronary heart disease and associations between coffee drinking and mortality and cancer incidence.
Av Bjarne Koster Jacobsen, 1988.
- 12.* Helse og ulikhet. Vi trenger et handlingsprogram for Finnmark.
Av Anders Forsdahl, Atle Svendal, Aslak Syse og Dag Thelle, 1989.
13. D. Health education and self-care in dentistry - surveys and interventions.
Av Anne Johanne Sjøgaard, 1989.
14. Helsekontroller i praksis. Erfaringer fra prosjektet helsekontroller i Troms 1983-1985.
Av Harald Siem og Arild Johansen, 1989.
15. Til Anders Forsdahls 60-års dag, 1990.
16. D. Diagnosis of cancer in general practice. A study of delay problems and warning signals of cancer, with implications for public cancer information and for cancer diagnostic strategies in general practice.
Av Knut Holtedahl, 1991.
17. D. The Tromsø Survey. The family intervention study. Feasibility of using a family approach to intervention on coronary heart disease. The effect of lifestyle intervention of coronary risk factors.
Av Synnøve Fønnebø Knutsen, 1991.
18. Helhetsforståelse og kommunikasjon. Filosofi for klinikere.
Av Åge Wifstad, 1991.
19. D. Factors affecting self-evaluated general health status - and the use of professional health care services.
Av Knut Fylkesnes, 1991.
20. D. Serum gamma-glutamyltransferase: Population determinants and diagnostic characteristics in relation to intervention on risk drinkers.
Av Odd Nilssen, 1992.
21. D. The Healthy Faith. Pregnancy outcome, risk of disease, cancer morbidity and mortality in Norwegian Seventh-Day-Adventists.
Av Vinjar Fønnebø, 1992.

22. D. Aspects of breast and cervical cancer screening.
Av Inger Torhild Gram, 1992.
23. D. Population studies on dyspepsia and peptic ulcer disease: Occurrence, aetiology, and diagnosis. From The Tromsø Heart Study and The Sørreisa Gastrointestinal Disorder Studie.
Av Roar Johnsen, 1992.
24. D. Diagnosis of pneumonia in adults in general practice.
Av Hasse Melbye, 1992.
25. D. Relationship between hemodynamics and blood lipids in population surveys, and effects of n-3 fatty acids.
Av Kaare Bønnaa, 1992.
26. D. Risk factors for, and 13-year mortality from cardiovascular disease by socioeconomic status. A study of 44690 men and 17540 women, ages 40-49.
Av Hanne Thürmer, 1993.
27. Utdrag av medisinalberetninger fra Sulitjelma 1891-1990.
Av Anders Forsdahl, 1993.
28. Helse, livsstil og levekår i Finnmark. Resultater fra Hjerte-karundersøkelsen i 1987-88. Finnmark III.
Av Knut Westlund og Anne Johanne Sjøgaard, 1993.
29. D. Patterns and predictors of drug use. A pharmacoepidemiologic study, linking the analgesic drug prescriptions to a population health survey in Tromsø, Norway.
Av Anne Elise Eggen, 1994.
30. D. ECG in health and disease. ECG findings in relation to CHD risk factors, constitutional variables and 16-year mortality in 2990 asymptomatic Oslo men aged 40-49 years in 1972.
Av Per G. Lund-Larsen, 1994.
31. D. Arrhythmia, electrocardiographic signs, and physical activity in relation to coronary heart risk factors and disease. The Tromsø Study.
Av Maja-Lisa Løchen, 1995.
32. D. The Military service: mental distress and changes in health behaviours among Norwegian army conscript.
Av Edvin Schei, 1995.

33. D. The Harstad injury prevention study: Hospital-based injury recording and community-based intervention.
Av Børge Ytterstad, 1995.
- 34.* D. Vilkår for begrepsdannelse og praksis i psykiatri. En filosofisk undersøkelse.
Av Åge Wifstad, 1996.
(utgitt Tano Aschehoug forlag 1997)
35. Dialog og refleksjon. Festskrift til professor Tom Andersen på hans 60-års dag, 1996.
36. D. Factors affecting doctors' decision making.
Av Ivar Sønnebø Kristiansen, 1996.
37. D. The Sørreisa gastrointestinal disorder study. Dyspepsia, peptic ulcer and endoscopic findings in a population.
Av Bjørn Bernersen, 1996.
38. D. Headache and neck or shoulder pain. An analysis of musculoskeletal problems in three comprehensive population studies in Northern Norway.
Av Toralf Hasvold, 1996.
39. Senfølger av kjernefysiske prøvespreninger på øygruppen Novaya Semlya i perioden 1955 til 1962. Rapport etter programmet "Liv". Arkangelsk 1994.
Av A.V. Tkatchev, L.K. Dobrodeeva, A.I. Isaev, T.S. Podjakova, 1996.
40. Helse og livskvalitet på 78 grader nord. Rapport fra en befolkningsstudie på Svalbard høsten 1988.
Av Helge Schirmer, Georg Høyer, Odd Nilssen, Tormod Brenn og Siri Steine, 1997.
- 41.* D. Physical activity and risk of cancer. A population based cohort study including prostate, testicular, colorectal, lung and breast cancer.
Av Inger Thune, 1997.
42. The Norwegian - Russian Health Study 1994/95. A cross-sectional study of pollution and health in the border area.
Av Tone Smith-Sivertsen, Valeri Tchachtchine, Eiliv Lund, Tor Norseth, Vladimir Bykov, 1997.
43. D. Use of alternative medicine by Norwegian cancer patients
Av Terje Risberg, 1998.

43. D. Incidence of and risk factors for myocardial infarction, stroke, and diabetes mellitus in a general population. The Finnmark Study 1974-1989.
Av Inger Njølstad, 1998.
45. D. General practitioner hospitals: Use and usefulness. A study from Finnmark County in North Norway.
Av Ivar Aaraas, 1998.
- 45B Sykestuer i Finnmark. En studie av bruk og nytteverdi.
Av Ivar Aaraas, 1998.
46. D. No går det på helsa laus. Helse, sykdom og risiko for sykdom i to nord-norske kystsamfunn.
Av Jorid Andersen, 1998.
47. D. The Tromsø Study: Risk factors for non-vertebral fractures in a middle-aged population.
Av Ragnar Martin Joakimsen, 1999.
48. D. The potential for reducing inappropriate hospital admissions: A study of health benefits and costs in a department of internal medicine.
Av Bjørn Odvar Eriksen, 1999.
49. D. Echocardiographic screening in a general population. Normal distribution of echocardiographic measurements and their relation to cardiovascular risk factors and disease. The Tromsø Study.
Av Henrik Schirmer, 2000.
50. D. Environmental and occupational exposure, life-style factors and pregnancy outcome in arctic and subarctic populations of Norway and Russia.
Av Jon Øyvind Odland, 2000.
- 50B Russisk utgave av Skriftserie 50
51. D. A population based study on coronary heart disease in families. The Finnmark Study 1974-1989.
Av Tormod Brenn, 2000.
52. D. Ultrasound assessed carotid atherosclerosis in a general population. The Tromsø Study.
Av Oddmund Joakimsen, 2000.

53. D. Risk factors for carotid intima-media thickness in a general population. The Tromsø Study 1979-1994.
Av Eva Stensland-Bugge, 2000.
54. D. The South Asian cataract management study.
Av Torkel Snellingen, 2000.
55. D. Air pollution and health in the Norwegian-Russian border area.
Av Tone Smith-Sivertsen, 2000.
56. D. Interpretation of forearm bone mineral density. The Tromsø Study.
Av Gro K. Rosvold Berntsen, 2000.
57. D. Individual fatty acids and cardiovascular risk factors.
Av Sameline Grimsgaard, 2001.
58. Finnmarkundersøkelsene
Av Anders Forsdahl, Fylkesnes K, Hermansen R, Lund E, Lupton B, Selmer R, Straume E, 2001.
59. D. Dietary data in the Norwegian women and cancer study. Validation and analyses of health related aspects.
Av Anette Hjartåker, 2001.
60. D. The stenotic carotid artery plaque. Prevalence, risk factors and relations to clinical disease. The Tromsø Study.
Av Ellisiv B. Mathiesen, 2001.
61. D. Studies in perinatal care from a sparsely populated area.
Av Jan Holt, 2001.
62. D. Fragile bones in patients with stroke? Bone mineral density in acute stroke patients and changes during one year of follow up.
Av Lone Jørgensen, 2001.
63. D. Psychiatric morbidity and mortality in northern Norway in the era of deinstitutionalisation. A psychiatric case register study.
Av Vidje Hansen, 2001.
64. D. Ill health in two contrasting countries.
Av Tom Andersen, 1978/2002.
65. D. Longitudinal analyses of cardiovascular risk factors.
Av Tom Wilsgaard, 2002.

66. Helseundersøkelsen i Arkhangelsk 2000.
Av Odd Nilssen, Alexei Kalinin, Tormod Brenn, Maria Averina et al., 2003.
67. D. Bio-psycho-social aspects of severe multiple trauma.
Av Audny G. W. Anke, 2003.
68. D. Persistent organic pollutants in human plasma from inhabitants of the arctic.
Av Torkjel Manning Sandanger, 2003.
69. D. Aspects of women's health in relation to use of hormonal contraceptives and pattern of child bearing.
Av Merethe Kumle, 2003.
70. Pasienterfaringer i primærlegetjenesten før og etter fastlegereformen.
Av Olaug Lian, 2003.
71. D. Vitamin D security in northern Norway in relation to marine food traditions.
Av Magritt Brustad, 2004.
72. D. Intervensjonsstudien i Finnmark. Evaluering av lokalsamfunns basert hjerte- og kar forebygging i kystkommunene Båtsfjord og Nordkapp.
Av Beate Lupton, 2004.
73. D. Environmental factors, metabolic profile, hormones and breast and endometrial cancer risk.
Av Anne-Sofie Furberg, 2004.
74. D. Det skapende mellomrommet i møtet mellom pasient og lege.
Av Eli Berg, 2004.
75. Kreftregisteret i Arkhangelsk oblast i nordvest Russland. Med en sammenligning av kreftforekomst i Arkhangelsk oblast og Norge 1993 - 2001.
Av Vaktskjold Arild, Lebedintseva Jelena, Korotov Dmitrij, Tkatsjov Anatolij, Podjakova Tatjana, Lund Eiliv, 2004
76. D. Characteristics and prognosis of long-term stroke survivors. The Tromsø Study.
Av Torgeir Engstad, 2004
77. D. Withdrawal and exclusion. A study of the spoken word as means of understanding schizophrenic patients.
Av Geir Fagerjord Lorem, 2005.

78. "Søkelys på samfunnsmedisinene." Evaluering av kommunal samfunnsmedisinsk legetjeneste, offentlig legearbeid og de forebyggende oppgaver i Fastlegeordningen.
Av Betty Pettersen og Roar Johnsen, 2005.
79. Prosjekt egenmelding Kristiansand kommune. Evaluering av kontrollert intervensjonsforsøk i stor skala, med utvidet rett til egenmelding i kombinasjon med økt og formalisert samhandling mellom arbeidstaker og arbeidsplassen ved sykefravær.
Av Nils Fleten og Roar Johnsen, 2005.
80. D. Abdominal aortic aneurysms: Diagnosis and epidemiology. The Tromsø study.
Av Kulbir Singh, 2005.
81. D. A population based study on cardiovascular diseases in Northwest Russia. The Arkhangelsk study 2000.
Av Maria Averina, 2005.
82. D. Exposure to exogenous hormones in women: risk factors for breast cancer and molecular signature.
Av Vanessa Dumeaux, 2005.
83. D. Repeated ultrasound measurements of carotid artery plaques in a general population. The Tromsø Study 1994-2001.
Av Stein Harald Johnsen, 2005.
84. D. Risk Factors For Fractures In Tromsø. The Tromsø Study.
Av Luai Awad Ahmed, 2005.
85. D. The quality and use of two health registries in Russia. The Arkhangelsk Cancer Registry and the Kola Birth Registry
Качество и использование двух медицинских регистров в России. Архангельск регистр рака и Кольский регистр родов
Av Arild Vaktskjold, 2005.

86. D. Haemoglobin, anaemia and haematological malignancies.
Av Tove Skjelbakken, 2006
87. D. The sick-listed - an under-recognised resource in handling sickness absence.
Av Nils Fleten, 2006.
88. D. Longitudinal changes in forearm bone mineral density in women and men from 25 to 84 years.
The Tromsø Study.
Av Nina Emaus, 2006.
89. D. Asthma and allergy in children. An epidemiological study of asthma and allergy in schoolchildren living in Northern Norway and Russia with respect to prevalence trends 1985-1995-2000, geographic differences in prevalence and biomarkers.
By Anders Selnes, 2006.
90. D. "Nå ska du høre ka æ mene med arv." Samisk forståelse av arv som en utfordring i medisinsk genetik.
Av Valeria Marton, 2006 -
Senter for Samisk Helseforskning
91. D. Sex steroids, bone loss and non-vertebral fractures in women and men. The Tromsø Study.
By Åshild Bjørnerem, 2007.
92. D. Substance use behaviour among ethnic diverse young people in North Norway in the 1990s.
"The North Norwegian Youth Study": A cross-cultural longitudinal study comparing smoking and drinking rates and patterns among young indigenous Sami and non-indigenous peers
Av Anna Rita Spein, 2007.
Senter for Samisk Helseforskning
93. D. Infection, inflammation and atherosclerosis.
Av Dag S. Halvorsen, 2007.
94. D. Hormones, Smoking and Mammographic Density in Postmenopausal Norwegian Women.
The Tromsø Mammography and Breast Cancer Study.
Av Yngve Bremnes, 2007.
95. D. Suicidal behaviour among indigenous Sami in Arctic Norway. A special focus on adolescents and young adults.
Av Anne Silviken, 2007.

96. D. Explaining the socioeconomic variation in incidence and survival of cancer. Analyses and multiple imputation of data from The Norwegian Women and Cancer Study and The Norwegian-Swedish Women's Lifestyle and Health Cohort Study.
Av Tonje Braaten, 2008.
97. D. Local Public Health Physicians in Norway from 1994 to 2002. Workload, work content, and interaction. A story of everyday life in primary health care.
Av Betty Johanne Pettersen, 2008.
98. D. Iron status and prevalence of hereditary haemochromatosis in a multiethnic population in northern Norway. The SAMINOR study, The Sør-Varanger study, The Tromsø V study
Av Ann Ragnhild Broderstad, 2008.
99. D. The consumption of lean and fatty fish, different dietary patterns, and the risk of cancers of various sites.
Av Dagrun Engeset. 2008.
100. D. Coercion in the delivery of mental health services in Norway.
Av Knut Ivar Iversen, 2008.
101. DD. Explaining risk reductions in medical practice: Prevention or postponement?
Av Peder Andreas Halvorsen, 2008.
102. D. Ankylosing spondylitis, aortic regurgitation, acetabular dysplasia and osteoarthritis of the hip. An epidemiological survey in a Norwegian Sámi population.
Av Knut Johnsen, 2009.
103. D. Helicobacter pylori and dyspepsia from a public health perspective. The Sørreisa gastrointestinal disorder study.
Av Anne Mette Asfeldt, 2009.
104. D. The Murmansk County Birth Registry (MCBR) The implementation and applicability of a population-based medical birth registry in the Russian Arctic
Av Erik Eik Anda, 2009.

105. D. Diet, dietary supplements and dietary change in cancer survivors and cancer-free persons - the Norwegian Women and Cancer study and the European Prospective Investigation into Cancer and Nutrition
Av Guri Skeie, 2009.
106. D. Some issues of provision and access to dental services in Norway
Av Birgit Abelsen, 2009.
107. D. A population-based study on cardiovascular risk factors and self-reported type 2 diabetes mellitus in the sami population. The SAMINOR Study.
Av Tove Anita Nystad, 2010.
108. D. Human exposure to perfluorinated compounds concentrations, dietary impact and molecular signatures.
Av Charlotta Rylander, 2010.
109. D. Hormone therapy use, sex hormone concentrations and gene expression - The Norwegian Women and Cancer study (NOWAC)
Av Marit Waaseth, 2010.
110. D. Abdominal aortic aneurysms: Risk factors and cardiovascular consequences. The Tromsø Study.
Av Signe Helene Forsdahl, 2010.
111. D. Young Adults and Seafood. Using the voice of consumers to develop new seafood product concepts aimed at increasing consumption
Av Themistoklis Altintzoglou, 2010.
112. D. The development and use of a new tool for estimating individual sun included vitamin D in epidemiological surveys.
Av Kåre Edvardsen, 2010.
113. D. Incidence of and risk factors for type 2 diabetes in a general population. The Tromsø Study.
Av Josepha Joseph, 2011.
114. D. Childhood Abuse - Pregnancy and Childbirth.
Av Mirjam Lukasse, 2011.
115. D. Ethnic discrimination and bullying in relation to self-reported physical and mental health in Sami settlement areas in Norway. The Saminor study
Ketil Lenert Hansen, 2011.

116. D. Body mass index and risk of malnutrition in community-living elderly men and women: Relationships with morbidity, mortality and health-related quality of life. The Tromsø and HUNT studies.
Av Jan-Magnus Kvamme, 2011.
117. D. Factors behind high cardiovascular disease mortality in Northwest Russia The Arkhangelsk study
Av Oleg Sidorenkov, 2011.
118. D. Functional ultrasound of the anal canal. The effect of pregnancy and childbirth.
Av Ingrid Petrikke Olsen, 2011.
119. D. Maternal concentrations, predictors and change in profiles of organochlorines, toxic and essential elements during pregnancy and postpartum. The Vietnamese Mother-and-Child Study and the Northern Norwegian Mother-and-Child Study.
Av Solrunn Hansen, 2011.
120. D. Morally bound medical work. An empirical study exploring moral conditions of doctors' everyday practice.
Av Kari Milch Agledahl, 2011.
121. D. A community-based factorial trial on Alzheimer's disease. Effects of expectancy, recruitment methods, co-morbidity and drug use. The Dementia Study in Northern Norway.
Av Fred Andersen, 2011.
122. D. Physical activity, osteoporosis, and fracture risk. Long-term associations in a general population.
Av Bente Morseth, 2011.
123. DD. Why don't we take a look at the patient? An anthropological analysis of how doctors become doctors.
Av Torstein Risør, 2011.
124. D. Aspects of health services in Sami areas.
Av Margrete Gaski, 2012.
125. D. Disease activity and outcome in juvenile idiopathic arthritis; a longitudinal cohort study in the Nordic countries.
Av Ellen Berit Nordal, 2012.

126. D. Carotid atherosclerosis, vascular risk factors and relation to cognitive test results. The Tromsø Study 1994-2008.
Av Kjell Arne Arntzen, 2012.
127. D. A doctor close at hand. A qualitative analysis of GPs' work in cancer care.
Av May-Lill Johansen, 2012.
128. D. Seasonal variation in incidence of acute myocardial infarction and cardiovascular disease risk factors in a subarctic population. The Tromsø Study.
Av Laila Arnesdatter Hopstock, 2012.
129. D. Nutrients and toxic elements in semi-domesticated reindeer in Norway. Nutritional and food safety aspects.
Av Amar Eltayeb Ali Hassan, 2012.
130. D. COPD in the elderly - diagnostic criteria, symptoms and smoking. Quantitative and qualitative studies of persons 60 years and older in The Tromsø studies.
Av Astri Medbø, 2012.
131. D. A study of fish consumption and cardiometabolic risk factors among the circumpolar population of the rural Nenets Autonomous Area in comparison with the urban population of Arkhangelsk County.
Av Natalia Petrenya, 2012.
132. D. Road traffic crashes in Arkhangelsk, Russia in 2005-2010.
Av Alexander Kudryavtsev, 2013.
133. D. Respiratory symptoms, lung function, and occupational exposure among seafood industry workers
A study among employees at Norwegian salmon factories and Russian North-West trawl fleet (Arkhangelsk)
Av Olga Shiryaeva, 2013.
134. D. Genetic susceptibility, lifestyle, ovarian hormones, and mammographic density - key factors in breast cancer development. The Norwegian Energy Balance and Breast Cancer Aspects-I Study.
Av Anita Iversen, 2013.

135. D. Physical activity, mortality and breast cancer risk.
The Norwegian Women and Cancer Study.
Av Kristin Benjaminsen Borch, 2013.
136. D. Retinopathy with and without diabetes: Risk factors and visual impairment.
The Tromsø Eye Study and a Norwegian screening study.
Av Geir Bertelsen, 2013.
137. D. Age-related macular degeneration: Prevalence and risk factors - a cross-sectional study. The Tromsø Study 2007/2008.
Av Maja Gran Erke, 2013.
138. D. Staphylococcus aureus nasal carriage - Interplay between host, microbe and the environment.
- The Tromsø Staph and Skin Study.
Av Karina Olsen, 2013.
139. D. Blood gene expression, lifestyle and diet. The Norwegian Women and Cancer Post-genome Cohort.
Av Karina Standahl Olsen, 2013.
140. D. Human biomonitoring of perfluoroalkyl substances and cyclic volatile methylsiloxanes. Concentrations in plasma, serum and whole blood from pregnant, delivering or postmenopausal women, and cord blood.
Av Linda Hanssen, 2013.
141. D. A population-based study of health care utilisation according to care level, socio-economic group, and continuity of primary care. The Tromsø Study.
Av Anne Helen Hansen, 2013.
142. D. Social determinants of self-rated health and cardiovascular disease among the Sami and other Arctic indigenous peoples.
The SLiCA study and the SAMINOR study
Av Bent-Martin Eliassen, 2013.
143. D. Vertebral fractures: prevalence, risk factors, and health-related quality of life.
The Tromsø Study 2007/2008.
Av Svanhild Waterloo, 2013.

144. D. Genital *chlamydia trachomatis* infections among adolescents in a high-incidence area in Norway: genotypes, prevalence, early sexual behavior and testing patterns - a cross-sectional study. The Finnmark High School Study (FHSS)
Av Kirsten Gravningen, 2013.
145. D. Associations between Primary Health Care - and Hospital Utilization among elderly People in Norway.
Av Trygve Sigvart Deraas, 2013.
146. D. Prenatal exposure to DDT and other selected environmental contaminants and their predictors in malaria and non-malaria areas in coastal KwaZulu Natal, South Africa.
Av Kalavati Channa, 2014.
147. D. Predictors of progression of ultrasound-assessed carotid artery atherosclerosis. The Tromsø Study 1994-2008
Av Marit Herder, 2014.
148. D. A study of occupational health among mine workers in Murmansk Oblast, Russia.
Av Morten Skandfer, 2014.
149. D. Psoriasis, overweight and metabolic syndrome. The Tromsø Study.
Av Kjersti Danielsen, 2014.
150. D. Smoking and incidence and mortality of colorectal cancer.
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