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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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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)

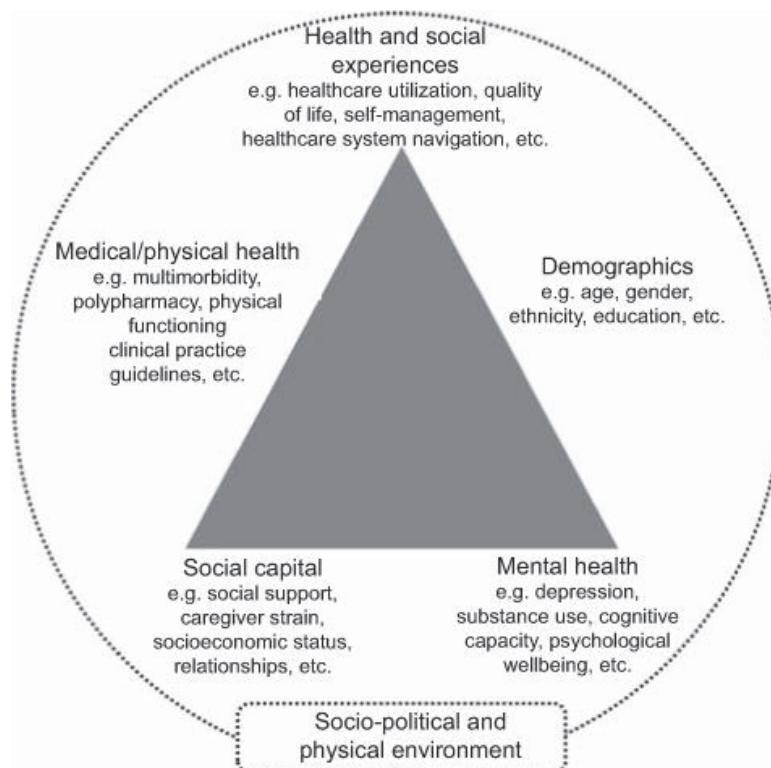
Even if multimorbidity is central, there are other types of criteria applied to identify patients with complex healthcare needs. The criteria defining which patients are entitled to a contact physician in Norwegian hospitals are severe disease, injury or conditions leading to the risk of malfunction 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

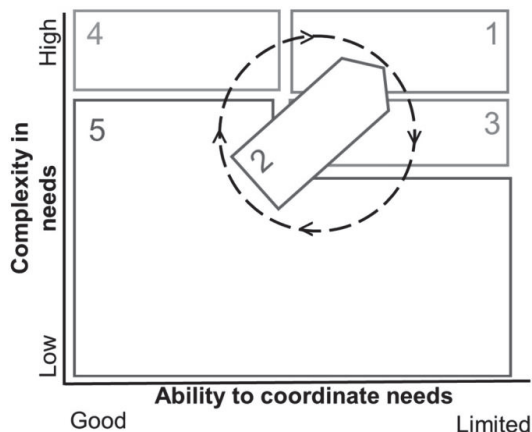
While the prevalence of specific diagnoses can be estimated as they are available in health records and registers, it is more difficult to estimate the number of patients with complex healthcare needs when these are attributed to other individual factors in the patients' situations, or characteristics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

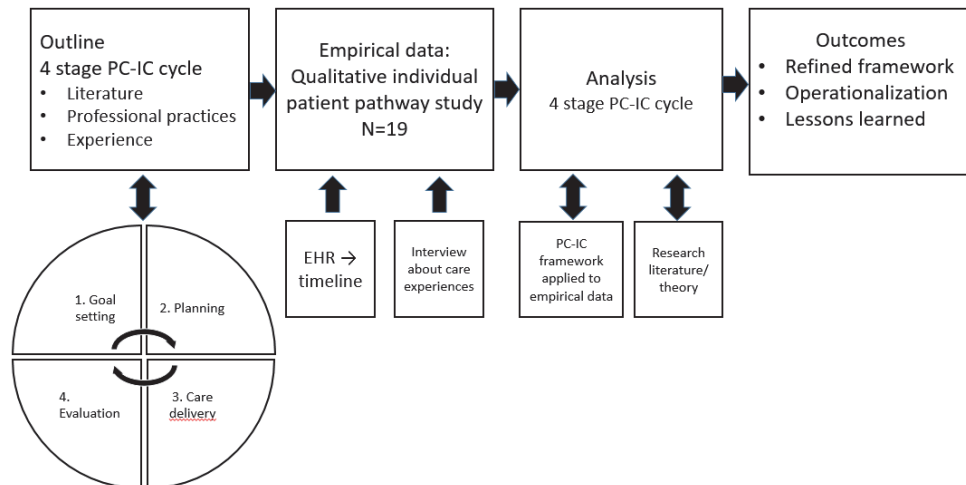
4.1.3 Paper III

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.

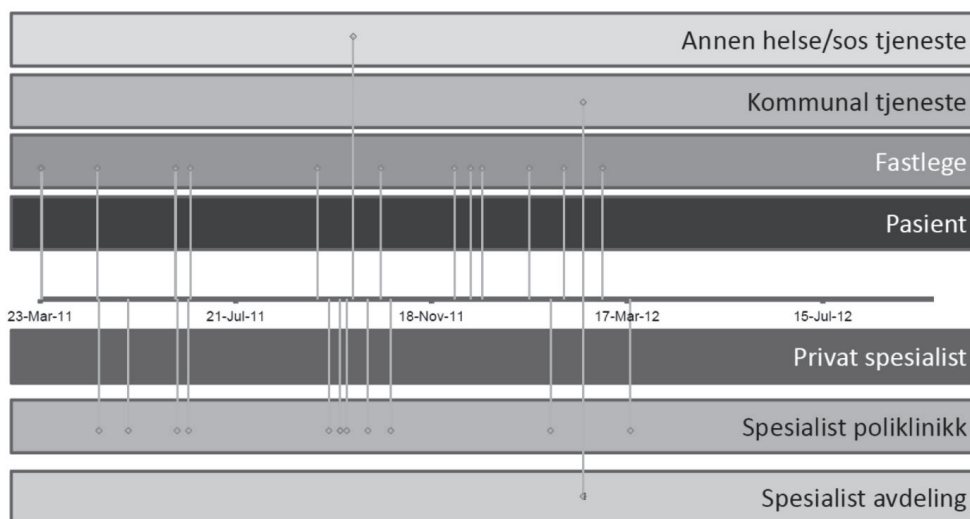
Two types of data sources were included: 1. Documentation of clinical encounters from the informants' patient health records in the hospital, at the general practitioner, and nursing services, respectively. 2. Data from individual semi-structured interviews about care experiences. The interview guide 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	Follow up of the individual patient before, under and after a hospital stay. Coordinate hospital services between units, departments, and professionals around the patient. Be the point of contact for the patient, collaborating professionals, external service providers, and institutions. Secure information and dialogue with the patient. Contribute to progression in work on the individual care plan when this is applicable	Be a stable contact-person for the patient regarding medical questions. 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. Contribute that the patient trajectory develops as planned. Establish contact with other professionals/units if necessary. Be available for medical questions from primary healthcare or other professionals. 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.

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 (Biringier, 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:

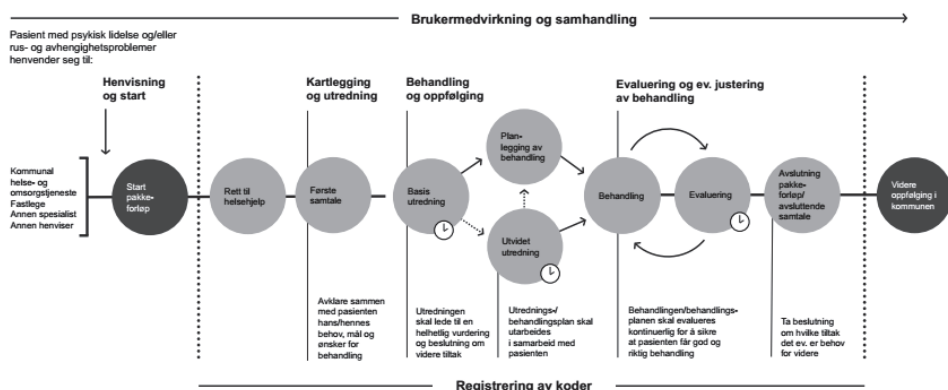
- In standardized pathways (e.g., for cancer, 2015a), quality is reported as the timely accomplishment of defined phases in pre-planned chains of care up to start of treatment, so that this may be evaluated in relation to the defined deadlines.
- In a recently implemented pathway model for mental healthcare 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.

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POLICY PAPER

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

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Introduction: In response to increase of patients with complex conditions, policies prescribe measures for improving continuity of care. This study investigates policies introducing coordinator roles in Norwegian hospitals that have proven challenging to implement.

Methods: This qualitative study of policy documents employed a discourse analysis inspired by Carol Bacchi's 'What's the problem represented to be?'. We analysed six legal documents (2011–2016) and selected parts of four whitepapers presenting the statutory patient care coordinator and contact physician roles in hospitals.

Results: The 'problem' represented in the policies is lack of coherent pathways and lack of stable responsible professionals. Extended personal responsibility for clinical personnel as coordinators is the prescribed solution. Their duties are described in terms of ideals for coherent pathways across conditions and contexts. System measures to support and orchestrate the individual patient's pathway (e.g. resources, infrastructure) are scarcely addressed.

Conclusions and Discussion: 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 regarding necessary system support for coordinators, is set on the agenda. Adoption of rhetoric from diagnosis-specific standardized pathways obscures unique challenges in creating coherent pathways for patients with complex needs.

Keywords: care pathway; coordinated care; continuity of care; complexity; integrated care; hospitals

Introduction

The number of people with chronic conditions and multiple health problems are growing [1, 2]. Common to these conditions, are the person's need for access to integrated healthcare from a range of services and professions over time to ensure continuity of care [3]. Modern healthcare organizations are responding to this need by organizing the services according to a process-perspective, as opposed to an episodic focus in care delivery [4, 5]. While

a multitude of concepts, definitions and models are in use [6], the aim of continuity of care is frequently expressed as coherent care pathways [4, 5, 7–9].

Similar to several Western countries [10–15], Norway has implemented national reforms aiming to overcome challenges due to fragmentation of services for persons with long-term healthcare needs. The Norwegian Coordination reform was introduced in 2008 and implemented in 2012 [16]. Central measures are transfer of tasks and responsibility from hospitals to primary healthcare, mandatory collaboration contracts between hospitals and municipalities, establishing new service units for more advanced treatment in primary healthcare, as well as the introduction of penalty fees for primary healthcare when they delay in receiving patients ready for discharge from hospitals [16]. These policies have implications for hospitals' roles and responsibilities; such as shorter hospital stays, restrictions to the most specialized treatment and care, as well as the need for enhanced collaboration and coordination towards primary healthcare [3, 17–19].

In addition to coordination measures on the administrative level, the Norwegian healthcare acts were amended

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from 2012 with new patient rights as well as statutory obligations to appoint patient coordinators on the operational level both in primary and specialized healthcare [20–22]. The hospitals became legally obliged to assign patient care coordinators to patients with complex or long-term needs of care [23]. Moreover, a new role for ‘contact physician’ came into force in 2016, both as a patient right and as a legal duty for the hospitals [24]. This responsibility applies to patients with serious conditions [20]. The authors had no relation or commitment with the policy development.

These new coordinator roles represented a reinforcement of a long-term initiative: Since 2001, Norwegian health authorities have focused on individual care plans and patient coordinator roles held by clinicians to secure individualized and integrated care, with gradually stronger legal regulations [11, 20]. Research prior to the Coordination Reform has shown that implementation of patient coordinator roles for complex needs had been slow, that professionals were reluctant to take on such roles, and that the proportion of individual care plans relative to the estimated number of persons who qualify for such plans was low [11, 17, 25, 26]. The Auditor General of Norway concluded in 2016 that, despite the extensive legislative efforts, the coordinator roles and individual care plans did not secure cohesive pathways for persons with complex or long-term needs according to the policy intentions [27]. Attempts to improve coordination at the operative level through legislation, has showed limited results also in other European countries [12, 28].

The aim of this study was 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. Our analysis was guided by sociologist Carol Bacchi’s analytic framework, ‘What’s the problem represented to be?’ (WPR) [29]. By examining how the ‘problem’ to be solved by these coordinator roles was constructed in the policy documents, we offer a critical reflection on the substantive content of this policy initiative [30].

Methods and materials

Design

Bacchi’s approach builds on that every policy proposal contains an explicit or implicit diagnosis of the ‘problem’ that the policy aims to solve. In the WPR-perspective, the ‘problems’ are not objectively given; rather they are constructed as part of the policymaking process [29, 30]. In accordance with Bacchi, we use quotation marks around the word ‘problem’ when it refers to the kind of change implied in a particular policy proposal and is not used in the traditional meaning [29]. The WPR-analysis is directed towards making the implicit ‘problems’ explicit, and to scrutinize them closely. In line with the aim of our study, we apply four of the six analytic questions posed by Bacchi to guide the analysis [29]. The WPR-analysis starts with ‘working backwards’ from the proposed policy intervention to make explicit what is defined as in need of change (Question 1). We then proceed with scrutinizing the con-

ceptual premises or discourses that enables particular promises and policies to be developed (Question 2). The next step is to identify and reflect upon what is left silent or unaddressed and thus is not made subject to policy goals or measures (Question 4). Finally, the implications for the roles or positions of those affected by the current ‘problem representation’ are in focus (Question 5). Bacchi’s remaining questions (3 and 6), that deal with how the ‘problem representation’ has come about and how it has been disseminated and defended, are not addressed in this study.

Historical background and context for the studied coordinator roles

Norway has a publicly funded healthcare system mainly free of charge for the citizens. Primary healthcare is organized by the municipalities and comprises of home care and nursing services, nursing homes, physiotherapy, occupational therapy etc. Every citizen has the right to a personal family doctor. The family doctors are gatekeepers for specialized healthcare and have a coordinating role for the totality of medical healthcare for the patient [31]. Most family doctors are organized as private enterprises, with designated public responsibilities [17]. Specialized healthcare is run and owned by national health authorities, and is organized into four regional health enterprises that manage 20 hospital trusts [17].

From 2001, individual care plans were introduced as a statutory right for those with complex care needs [32], and as a duty for healthcare personnel both in hospitals and primary care (**Table 1**). Individual care plan is a personally tailored plan built around prioritized personal goals for the patient, covering needed services from different sectors and units. It is central that the plan is developed in a partnership between the patient and a multidisciplinary team of professionals from relevant service units, led by an individual care plan coordinator from the clinical staff. It is the duty of the plan coordinator to recruit and organize the participation of relevant professionals for this work [17]. At the same time, Norwegian hospitals were obliged to appoint a ‘patient responsible physician’ for all hospital patients [33]. As previously mentioned, several amendments were made in the healthcare acts and regulations as part of the Coordination reform in 2012 [22]. The patient care coordinator for patients with complex or long-term needs of care became a freestanding role, regardless of if the patient needed or wanted an individual care plan [23]. This modified coordinator role replaced the ‘patient responsible physician’.

A parallel process in Norwegian hospitals, also focusing on pathway coordinator roles, was the development and implementation of standardized clinical pathways for 28 types of cancer in 2015 [34]. A clinical pathway describes a process within a hospital or clinic, whereas a care pathway includes discharge, follow up and out-patient clinic activities [9]. The cancer pathways are designed according to international guidelines that are customized to the local contexts. It is mandatory that each pathway have a cancer pathway coordinator in a designated position to guide the patients through the programme, to monitor and register

Table 1: Historical development of coordinator roles in Norwegian hospitals 2001–2016.

Coordinator roles in hospitals	Year of introduction or change			
	2001	2012	2015	2016
Individual care plan that includes a personal coordinator for patients with long-term complex needs. (Patient right and healthcare obligation by law, 2001)	X	X	X	X→
Patient responsible physician. All patients. (Regulations 2001)	X			
Patient care coordinator in specialized healthcare for patients with long-term complex needs, whether they want an individual care plan or not. Preferably a physician. (Healthcare obligation by law 2012–2015)		X		
Coordination unit in each hospital. Responsible for the hospital's work with individual care plans and coordinators. (Regulated since 2001, obligation by law in 2012)	X	X	X	X→
* Patient care coordinator in specialized healthcare. The coordinator may have any health profession. (Law amendment 2015)			X	X→
* Hospital contact-physician for seriously ill. (Patient right and healthcare obligation by law 2016)				X→

* These two roles are the focus of this study.

that the events follow the plan, as well as to participate in multidisciplinary work and take care of logistics. The cancer pathway coordinator role is not decreed by law. The national implementation support to the standardized cancer pathways has been extensive [34].

Materials

In accordance with Bacchi [29] we chose the law paragraphs in the Specialized Health Services Act covering the two legally obligated coordination roles as an entry to the field [20]. The included documents are presented in **Table 2**, and is referred to in the result section by the document numbers in the table (in round brackets). Further, we included all the legal documents concerning the responsibility of specialized healthcare related to these roles: The regulations (2) and directives (3) applicable for the chosen law paragraphs, the government law-proposition that introduced the amendment concerning the contact physician (4), and the national guideline that includes the patient care coordinator role (5). Finally, we included the national guideline for implementing the contact physician that was published during the process of the study (6). From the documents that comprised of more than the studied roles, paragraphs and sections covering the chosen coordinator roles were selected (specified in **Table 2**). We have excluded parliamentary proceedings and media communications. To provide context and historical background, four whitepapers (7–10) that introduce, justify or refer to the studied roles and their predecessors were included.

Analysis

We started with mapping central characteristics of the two coordinator roles based on full text readings of the selected documents and document sections. AH consecutively entered condensed descriptions of the roles in a table (Microsoft Excel) according to dimensions that were inductively developed.

The next step in the analysis of the selected documents and document parts were conducted within NVivo, a computer program for qualitative data analysis [41]. The following terms were identified as central in the characteristics of the coordinator roles in the aforementioned mapping process: coordinator, contact-physician, continuity, coherence and compound words containing the Norwegian word ‘forlop’ (English: pathway, trajectory, course, path). Automatic text searches were conducted in NVivo for these terms. This was done in order not to miss any of the text covering central concepts describing the roles, tasks and aims.

At this point, two of Bacchi's guiding questions for the analytic process [29, p. 2] were applied: 1. What's the problem represented to be? 2. What presuppositions or assumptions underlie this representation of the 'problem'? First, the full text was read in the light of these questions. Subsequently, the result was validated through reading of the central paragraphs that had been identified through the text searches in NVivo. 'Answers' to each question found in the texts were recorded successively in memos. Further, text excerpts representing central themes were included.

Memos covering analytic reflections were written during the process of coding and in discussions with the co-authors when themes began to take shape that were relevant for the analysis. Then the memos were read together with the full texts and the coded texts, and an analytic matrix was made in a spreadsheet. The themes were gradually condensed and abstracted both within and across the studied coordinator roles. The findings were then categorized into the two themes presented in the second part of the result section; "What is the problem represented to be?".

Finally, the fourth and fifth of Bacchi's questions were employed as a basis for the discussion section; 4. What is left silenced? 5. Which effects are produced by this 'problem representation'?

Table 2: The included documents.

Document number, document title and which parts of the documents are analysed	Type and status	Topic covered*	Publication year
1. Specialized Health Services Act [20]. §§ 2–2, 2–5a, b and c	Current legislation	PCC & CP	1999, updated 17.6.2016
2. Regulations to the Specialized Health Services Act and the Health and Care Services Act concerning rehabilitation, individual plan and patient care coordinator [35].	Regulations covering the patient care coordinator role	PCC	2012
3. Directive to the Specialized Health Services Act [23]. p. 23–27	Circular	PCC	2013
4. Law proposition to the Parliament, Prop. 125 L. Amendments to the Specialized Health Care Act. [22]. Chapters 1–8, p. 5–38 and 10, p. 43–46	Proposition The proposed amendment to the Specialized Health Services Act was approved in November 2015	PCC & CP	2014–2015
5. Guidelines for patient care coordinator [36]. Chapter 13, p. 82–93	Document with recommendations and clarifications for how to understand the law paragraphs and regulations regarding rehabilitation, individual care plan and coordinator	PCC	2015, updated 23.2.2017
6. Guidelines for contact physician [37]. Chapters 1–8, p. 1–33	Document with recommendations and clarifications for how to understand the law paragraphs and regulations regarding contact physician in specialized healthcare	PCC & CP	2016
7. The Coordination Reform. Proper treatment – at the right place and right time. Report No. 47 (2008–2009) to the Storting. [16]. Chapters 1–5, p. 11–53 and 10, p. 111–114	Report to the Storting from the Minister of Health and Care Services	Background and context	2009
8. NOU 2005: 3. From piecemeal to whole – an integrated health service [38]. Chapters 1, 2, p. 11–21, 4, p. 40–48, 6 and 7, p. 67–87	Official Norwegian Report delivered to the Ministry of Health and Care Services	Historical background	2005
9. NOU 1997: 2 The patient first! Leadership and organization in hospitals [39]. Chapters 2, p. 15–16 and 8, p. 92–108	Official Norwegian Report delivered to the Ministry of Social Affairs and Health	Historical background	1997
10. Meld.St.11 (2015–2016) National health- and hospital plan 2016–2019. [40]. Chapter 7.3, p. 57–58	Report to the Storting from the Minister of Health and Care Services	Current plan for hospitals	2015

*The abbreviation PCC is used for patient care coordinator and CP for contact physician in table 2.

A log was kept to document the analytical steps taken during the process.

Results

Characteristics of the coordinator roles

Table 3 presents an overview of central characteristics for the patient care coordinator and the contact physician respectively: purpose, tasks, assigned profession and target group, as well as legal status and implementation status.

'What is the problem represented to be?'

We identified the following overarching 'problem' that the introduction of statutory patient care coordinator and contact physician roles in hospitals are designed to solve:

The hospitals cannot be trusted in providing coherent care pathways, nor do they ensure responsible and

available clinicians for patients with complex long-term needs of care.

The central aspects of this 'problem representation' were categorized into two themes: 1. 'Lack of pathway-organized services' and 2. 'Lack of stable and responsible clinicians. Separating the desired service-organization (theme 1) from the responsibility for providing it (theme 2), helped highlight important and contrasting topics. However, the themes are closely related and thus overlap somewhat in the following presentation.

Lack of pathway-organized services

The central concepts used in the descriptions of the two coordinators' roles in the policy documents express ideals of continuity and holism, and that healthcare is planned and delivered as a process around the individual patient in the form of a coordinated care pathway or trajectory.

Table 3: Central characteristics of the two coordinator roles.

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	Follow up of the individual patient before, under and after hospital stay. Coordinate hospital services between units, departments, and professionals around the patient. Be the point of contact for the patient, collaborating professionals, external service providers and institutions. Secure information and dialogue with the patient. Contribute to progression in the process in the work on the individual care plan (ICP) when this is applicable*	Be a stable contact-person for the patient regarding medical questions. 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. Contribute that the patient trajectory develops as planned. Establish contact with other professionals/units if necessary. Be available for medical questions from primary healthcare or other professionals. 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'.
Assigned profession	Healthcare personnel. (From 2012–2015: 'Coordinator should preferably be a physician'. This 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 serious conditions who are in need of treatment or follow up from specialized healthcare for a period of time.
Criteria defining target group	Expected needs of services for the patient from different departments, units and professions in specialized healthcare over time, and the need of coordinated services.	The severity of the condition; risk of disability or death, comorbidity, expected progression. Duration: Need of treatment more than 3–4 days. Need of more than one follow-up consultation.
Legal status	Obligation for specialized healthcare (Specialized Health Services Act). Not a legalized right for the patient.	Obligation for specialized healthcare (Specialized Health Services Act). 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 [27].	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).

* From being a common responsibility for all healthcare services, the main responsibility for individual care plans was assigned to the municipalities from 2012. When patients need services from both primary and specialized healthcare, the hospitals' responsibility was confined to informing the patients, reporting patients' needs of individual care plans to the municipalities, and to collaborate and contribute according to the needs of the individual patient. Specialized healthcare must develop the plan together with the patient, if he or she do not need services from the municipality (5).

“The coordinator must accommodate the patients' needs for a continuous and holistic patient pathway” (3, p. 25).

pathways, many different clinicians involved, poor information flow, and lack of continuity and overview” (10, p. 57).

The arguments in policy documents for establishing the coordinator roles show the type of 'problems' that the coordinators should help alleviate.

“Hospitals are complex organisations. Patients move between outpatient and inpatient services, x-rays, labs, and different clinical departments, and between hospital and primary health and care services. It is well documented that the risk for failure is greatest during transitions between services. Many patients complain about fragmented

We see similar descriptions of ideals and challenges in the other documents (4, 5, 6, and 8). The key terms used depict a planned process along a timeline. They include; 'pathway', 'patient pathway', 'cohesive pathway', 'standard pathway', 'course of treatment', 'patient trajectory' and similar. These terms are used in conjunction with words as continuous, holistic, coherent and coordinated. Clear definitions of these concepts are not offered. To describe how the different key terms are applied in the documents, they are categorised in three different dimensions of care; a safety and quality dimension, a temporal

and organizational dimension, and a patient involvement dimension.

The dimension of safety and quality in care

The regulations of these coordinator roles state the ideal that the patients at all times must feel safe and secure in their encounters with healthcare.

“It is vital that patients with a serious illness, injury or disability, and also their next of kin, feel secure throughout the patient trajectory” (4, p. 10).

The coordinators are ascribed a role of monitoring and adjusting the ongoing service provision to safeguard quality and patient safety for the individual patient.

“The aim [of contact physician] is increased security and predictability for the patient and next of kin, improved quality and cohesion in the medical services” (10, p. 57).

The documents do not outline further how to interpret safety and quality. Nor are the tasks and magnitude of the responsibilities for the coordinators described when it comes to ensuring each individual patient’s experience of security, overview, predictability and coherence at any stage in the healthcare trajectory.

The temporal and organizational dimension of care

The descriptions of the coordinator roles underline the importance of seeing the elements of healthcare in a broader holistic perspective, or as a phase in a longer trajectory (temporal dimension), where attention to transfers is vital in preventing fragmented care (organizational dimension) (5).

“Achieving a good pathway requires good collaboration, logistics and communication between the various service localities and levels of care” (4, p. 10).

In this perspective, the ideals of continuity and holism imply services delivered in a timely fashion according to a plan, along a timeline adapted for the individual patient. It is specified that the coordinator shall ensure coordination of all the healthcare services that are relevant in connection to a hospital stay (3). In the guidelines (5, 6) it is referred to the standardized pathways that in 2015 were implemented in Norwegian hospitals for 28 cancer diagnoses [34], and that the cancer pathway coordinators may fill the role as ‘patient care coordinators’.

The dimension of patient involvement in care

The coordinators are expected to ensure that the process of planning and performance of care fulfils specific ideals of person-centred care. One aspect is to ensure user participation and patient influence through co-creation of care (5).

“The coordinator is responsible for following up input from patients and their families, and for

ensuring user involvement and good dialogue” (3, p. 25).

The law paragraph (1, §2–5 a) states that the patient care coordinator shall safeguard progress in developing and following up the patient’s individual care plan when applicable. The reference to the statutory individual care plan signals specific requirements for personalisation of the care planning and delivery in the form of a written plan based on personal goals. Additionally, it signals that the scope of what is within the coordinators’ responsibility is the patient’s ‘coping with life’, not merely treatment or healthcare.

Lack of stable and responsible professionals

The law requires that hospitals appoint patient coordinators from clinical staff to be responsible for ensuring continuity of care for individual patients (1, §2–5 a and §2–5 c). This implies an assumption that current fragmentation is the result of lack of effort on the part of coordinating professionals. Thus, the ‘problem’ becomes the lack of a responsible and available person.

The patient care coordinator role is described in the documents by terms such as; ‘ensure’, ‘provide’, ‘secure’, ‘safeguard’, ‘take responsibility for’, ‘take care of’, ‘at any time hold the main responsibility for’, and ‘have a central role in’. These reflect expectations that the coordinators should take on a high degree of personal responsibility. The tasks connected to these responsibilities include; ‘the needed follow-up of the individual’, ‘coordinated and individualized services’, ‘co-ordination with external services’, ‘progress in development of individual care plan’, and ‘dialogue and user participation’ – among others (1, 2, 3, 5, 6).

“The coordinator is a service provider responsible for ensuring necessary follow-up and coordination of the services, as well as progress in work with the individual care plan” (5, p. 83).

Some of the same terms are used to describe the role of the contact physician: ‘Keep the complete overview over the patient trajectory’, ‘contribute to ensuring that the trajectory develops as planned’, and ‘[it is recommended that the contact physician] hold the statutory role of being responsible for information to the patient and for the patient’s record’ (4, 6).

“Patients will still meet several physicians during the process, but patients and next of kin must feel secure that there is one physician who has a particular responsibility for them” (6, p. 5).

The way the pathway ideals and responsibilities are described, it is not clearly specified whether the pathway coordination responsibilities for these coordinators are limited to the hospital treatment, the totality of the patient’s healthcare encounters across institutions, or if it should cover a wider coping with life-perspective. Particularly the references to the individual care plans in the descriptions of the patient care coordinator, indicates that the scope of this role includes the patients’ process of ‘coping with life’ in addition to disease-related treatment

and the logistics of the healthcare events both before, under and after hospital treatment (3, 5). Also the references to 'necessary follow-up', 'complete overview of the patient trajectory', and 'coordination with external services' express wide and undefined responsibilities.

It is recommended that the patient have only one contact physician, also when several healthcare units are involved (6). The responsibility of the contact physician is thus not limited to the treatment within the unit where the physician is organized, the areas of the physician's specialization, or the period of hospital stay (6). Additionally, the guidelines for the contact physician explicitly state that taking on this role in no way changes the responsibilities of existing roles like 'treatment responsible physician' and 'responsible surgeon' (6, p. 6). In the same way, the responsibility of the patient care coordinator is to interact with and orchestrate personnel both within and outside the unit or institution that have or will have treatment or follow-up responsibility for the patient (5).

One of the main aims of both roles for patients with long-term, complex needs is to provide relational continuity between the patient and a particular healthcare professional who is available over time, and who is well informed about the patient's situation and the relevant services to be coordinated (5, 6).

"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" (6, 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" (5, p. 83).

Patients with a combination of complex long-term needs and serious illness qualify to have both a contact physician and a patient care coordinator (1). In addition, those who have a cancer diagnosis, for which a standardized pathway has been implemented, may also have a cancer pathway coordinator (6). The tasks and responsibilities are to some extent differentiated between the roles in the current guidelines for situations where the patient qualifies for more than one of these coordinators (4, 5, 6): The care coordinator's role should be limited to the logistical coordination and to ensure progress in individual care plan process. The contact physician's role is mainly to be informed and available for the patient, next of kin and collaborating healthcare personnel in relation to medical issues. While the cancer pathway coordinator is recommended to fill the role of patient care coordinator if the patient needs both (5, 6). The need of close collaboration and clarification of the roles towards the patients is emphasized (6). Further distinctions between responsibilities and roles in varying circumstances are not offered in the documents, nor are questions related to capacity and authority within and between the roles addressed.

Discussion

This study found that the policies prescribing contact physicians and patient care coordinators are designed to solve the 'problems' that the hospitals do not provide coherent care pathways for patients with complex long-term needs of care, and that they do not ensure responsible and available clinicians as stable contact persons for these patients. Professionals in clinical staff should be appointed as coordinators who are assigned a personal responsibility for realization of healthcare that is planned and delivered as a process around the individual patient in the form of a coordinated care pathway or trajectory. This covers quality and security, time/space logistics and processes that ensure patient involvement. The coordinators are also expected to be available for the patients, and responsible on behalf of the system, over time and across units.

Common pathway rhetoric – different premises

The call for pathway approaches in the studied documents resonates with the central public discourse expressing the ideal of process-organized services aiming at efficient delivery, equality of healthcare and continuity of care for patients [4, 5, 7, 8]. The many dimensions of care pathway ideals described as the coordinators' responsibility in the documents, can be expected to represent challenges for professionals and leaders responsible for realizing these. Different understandings of the care pathway concepts may embody differing, and in some cases even contradictory logics, processes and knowledge bases [42].

Complexity is a key concept used in defining the target groups for the hospitals' obligation to appoint patient care coordinators. Complexity is defined as the need for services from two or more units or professions over time [23]. Thus, the predictability of the care process and the needs for services and coordination assistance will show considerable variation within the target group. This will in turn have an impact on which type of care pathway model that is relevant in each case. The European Pathway Association distinguish between 'chain models' for high degree of predictability of needs and agreement about treatment, 'hub models' with a case manager for less predictable processes, and 'web models' for changing and unpredictable situations [7]. For the part of the target group with multimorbidity and serious illness that might be progressive or result in severe disabilities, a variety of services may become relevant at different stages for the individual patient [43]. Processes may be messy due to parallel ongoing assessment and treatment, many units and actors involved, and unpredictable disease progression or complications, or because of the patient's personal situation [44]. Thus, there will be variation in what is needed to provide coherent pathways for the individual patient according to the policy ideals. However, the policies do not address how variation in degree of complexity of the patients' needs may have consequences for the coordinator roles.

Additionally, the pathway rhetoric in the studied documents coincides with the rhetoric around standardized clinical pathways in the hospitals [9, 45]. The Norwegian cancer pathways is an example of such pathways [34]. These are preplanned 'chains of care', often with

pre-booked consultations along a defined timeline, organized multidisciplinary collaboration and dedicated coordinator positions with defined mandates and responsibility for facilitating, monitoring, customizing and documenting the patient flow. For this type of pathways, limited to a defined diagnosis or treatment procedure, there are clinical guidelines to be followed and a common knowledge base to build on [4]. The premises for such pathways are sufficient predictability of the patients' needs and agreement about treatment to make a planned chain of care [7]. Moreover, the standardized pathways are limited to a particular context or institution, and the organization of these pathways builds on local workflow analyses [45]. The statutory coordinator roles, however, are universal. Thus, the coordinators are expected to realize tailored pathways based on the individual patient's needs in hospital units and beyond with various infrastructure available.

The expansion of process-organized ideals for patient pathways from one diagnosis, to encompassing multimorbidity or complex service needs, as described by Fineide and Ramsdal [4], were also identified in our investigation. Similarly, we found a vertical expansion of the care to be organized, from relatively short intra-organizational processes, to cover transfers between services across organizational borders over long periods. Consequently, the knowledge base may be both controversial and uncertain [4], thereby failing to fulfil a central precondition for standardizing pathways [7]. Nevertheless, we see that the same concepts are used, without problematizing these factors. The hospitals are even advised to look to the implementation of the cancer pathways [22] for how to meet the expected challenges related to implementing the contact physician role. The policy documents do not mention the extensive preparatory work, structural organization and dedicated professional resources on which the cancer pathways are based [34]. No such processes or resources are referred to for the two studied coordinator roles. Beyond creating an individual care plan, no models or methods are suggested.

Based on the above, we suggest that the use of rhetoric based on clinical pathways, obscures the particular challenges related to creating coherent care pathways for patients with long-term needs, multimorbidity, low predictability of needs, or involvement of several service units and institutions. Additionally, we argue that as a result of the 'problem representation' inherent in the studied policy documents, the diversity of patient needs and preferences as well as the heterogeneity of current hospital work practices are left silent. Thus, the need of structural arrangements like availability of multidisciplinary resources, organized teamwork, mandate to cross borders, or process redesign are not thematised.

Personal versus systemic responsibility

Both the studied coordinator roles depend on assigning personal responsibility to a named and available clinician. Seemingly, this is a reasonable solution to fragmented services and low personal continuity as experienced by patients in hospitals. Having one trusted clinician, who helps navigate the system and takes personal responsibility

for patient involvement and care planning, is understandably highly valued by patients with long-term healthcare needs [44, 46]. Nevertheless, as others have noted [47], designating responsibility to individual professionals may threaten the collective organizational responsibility needed to ensure 'system continuity' on a 24/7 basis in the hospital. Krogstad et al. point out differences between visible continuity measures such as when the patient meets the same professionals every day (front stage continuity), and continuity that is taken care of behind the scenes within an organizational system securing shared information and responsibility (back stage continuity). The current 'problem representation' is conceptualized as lack of 'front stage continuity' [47], and thus the answer is that professionals extend their personal responsibility for the follow-up of individual patients.

Still, some sort of personal responsibility is not new to healthcare. Conscientious healthcare professionals engage daily in detecting and bridging gaps of care, and work to build continuity for patients [48]. Organizing work is often invisible, as when nurses create continuity for patients across shifts, departments and institutions through a proactive identification of actions that Allen call "trajectory mobilisation" [49]. This type of work demands competence and experience, and it is context sensitive [50, 51].

Additionally, numerous coordinator roles are established on a system level in hospitals; some in dedicated positions, with earmarked resources and infrastructural support. These may be devoted e.g. to patient discharge [52], to the follow up of patients with a particular diagnosis [53], or to patients undergoing a certain treatment procedure [54]. However, the studied Norwegian coordination policy refer in a very limited degree to existing coordination measures, established coordinator roles, or to research on such. Thus, those responsible for implementing the new statutory coordinator roles must agree on how to interpret the policy demands, and how to design the new roles in relation to existing resources in the particular context.

Extended and overlapping scope of responsibility

The introduction of the patient responsible physician in 2001 (Table 1), was found to disrupt established work practices and distribution of responsibility among nurses and physicians in hospitals [51]. The hospital trusts and professionals' unions that submitted consultation responses to the proposition of the law amendment introducing contact physician in 2014 [55], expressed concern that this obligation of personalized responsibility would interfere with established roles and create new grey zones of responsibility in the hospital, thus increasing the risk of poorer security and quality of care for the patients. While sharing the ideals of process-organized healthcare around the individual patient, several considered this arrangement neither feasible nor sustainable [55].

The two studied hospital coordinators' responsibility covers coordinating care in relation to hospital admissions, including before, between and after hospital treatments [36, 37]. Hence they are expected to choose their

actions and priorities, and allocate the needed resources based on an overall perspective of the patient trajectory [56], thereby extending their professional responsibility both in time and scope. This includes defining when there is a need to apply the statutory coordinator role, and negotiating the practical performance of the role in the local work practices.

This extended duty also actualizes questions related to distribution of responsibility for care coordination between specialized and primary healthcare. The family doctor in primary care has a long-standing responsibility of coordinating medical healthcare for the individual patient [31]. The new contact physician in hospitals now has a similar duty, though with the main focus on the specialized healthcare [37]. The guideline for contact physicians specify that implementing the new roles should not entail changes to current responsibilities between primary and specialized healthcare [37]. The patient care coordinators in primary healthcare are given a nearly identical duty as those in hospitals [35]. Additionally, the municipalities are assigned the main responsibility for coordination through the individual care plan when the patient needs services from both sectors [35]. The new statutory coordination responsibilities for the hospitals thus seem to overlap those of primary healthcare. Hence, the distributions of responsibility between coordinators in the different sectors are subject to negotiations in each given situation. Limited system support is available for such processes. The statutory Coordination units are responsible, on behalf of the hospital and the municipality respectively, for realization of individual care plans and patient care coordinator roles as well as for supporting the coordinators [35]. Two unpublished surveys by the first author show, however, that a majority of these units in hospitals have limited capacity and authority. Often they consist only of one part-time position, and have limited authority due to a low position in the organization. Many also describe a low degree of leadership support.

A coordinator role that implies actions beyond both professional and institutional mandates, leads to authority challenges such as restricted access to relevant arenas and information, as well as lack of decision-making authority needed in the realization of individual care pathways across units and sectors. An apparent paradox is that at the same time as responsibilities for the follow up of patients with long-term complex needs are transferred from hospitals to primary healthcare as part of the coordination reform, the hospitals' duties for cross-sector coordination are both extended and strengthened through legal obligations.

Limitations

To the best of our knowledge, the document sample covers the current Norwegian legislation on our topic. An inclusion of governmental debates, media communication and a wider range of governing documents could have broadened the scope and analysis.

One of the main aims of Bacchi's post-structural discourse analysis is to disclose how the way the 'problem' is represented in policy, makes certain subject positions

possible or available [30]. The focus of our study is limited to the subject positions of healthcare providers. The study would have been strengthened by an examination of the policies' implications for the patient role and position, and for the fulfilment of patients' rights.

An empirical study of stakeholders' understanding of these policies would offer important complementary insights.

Conclusion

Our analysis shows that the lack of coherent pathways, as well as the lack of stable and responsible professionals for patients with complex needs are represented as the 'problems' to be solved by extending individual healthcare professionals' scope of responsibility in roles as coordinators. We suggest that the policies' construction of the 'problem' as a responsibility issue shows that Norwegian authorities focus on 'front stage continuity'. Professionals and leaders in hospitals emphasize 'back stage' or system continuity, and have criticized the policymakers for not taking into account the diversity of patient needs, the heterogeneity of hospital practices and existing coordination work.

Further, how clinicians are to fulfil their expanded roles within existing work practices is left unaddressed. The adequacy of hospital professionals in clinical positions as coordinators responsible for patient pathways depends on both contextual and personal factors. In some hospital units, coordinators may have access to appropriate system support such as suitable information systems, multidisciplinary resources and organized teamwork, while others lack all such resources.

The studied policy documents use a 'pathway rhetoric' that is captivating. However, these concepts are established for disease-specific clinical pathways. 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 with involvement of several professionals, service units and institutions.

Finally, we argue that it is demanding to question the framing of the 'problem' and further to create opportunities for discussing alternative understandings, when personally responsible coordinators as the instrument for achieving the goal of coherent care pathways is obligated by law and seemingly solves an obvious challenge.

Additional File

The additional file for this article can be found as follows:

- **List of analysed documents.** The included documents and where to find them on the Internet. DOI: <https://doi.org/10.5334/ijic.3617.s1>

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Competing Interests

The authors have no competing interests to declare.

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Paper II

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

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Abstract

Introduction: Various efforts aim to enhance continuity of care for patients with long-term health-care needs. Since 2012, Norwegian hospitals are mandated to appoint individual care coordinators for patients with complex needs to ensure continuity in the care pathway. New roles must meld with current practice. Implementation has been slow. This study investigates current care coordination across hospital contexts, from the perspective of health-care providers, a scarcely researched area.

Methods: A qualitative study using semi-structured individual, duo, and group interviews with 16 purposefully selected Norwegian health-care providers from different hospitals, departments, professions and with various roles. A thematic cross-case analysis using systematic text condensation was performed.

Results: Common for the interviewees' care coordination experiences was to "keep one step ahead." The scope of their coordination activities varied from diagnostics and treatment to orchestrating long-term, cross-sectional multi-disciplinary care. This work was often performed without designated resources. The interviewees applied experience, knowledge, and sensitivity when defining the patients' needs and searching for resources to orchestrate coordination work. They strived to balance the needs of patients with the resources available and adjusted the continuity ambitions on behalf of their patients to what they considered doable in the relevant contexts. However, many told of negotiating special solutions for selected patients with particularly complex needs.

Discussion: Care coordination for patients with complex needs emerged as diverse and context-sensitive. Acknowledgement of coordination activities that go beyond established workflow routines and clinical pathways, together with flexible leadership support and accessible infrastructural resources are needed.

Keywords

Qualitative research, health personnel, hospital departments, delivery of health care, long-term care, continuity of patient care

Background

Fragmented care is a great challenge for people living with complex, long-term needs of health care.^{1,2} A growing number of patients are in need of health services from multiple providers and units over time^{3,4} and they request improved care coordination.^{5,6}

Feeling secure when crossing care boundaries, having the opportunity and the means to be involved in care on their own premises, and having access to a contact

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person who knows them have been found to be central values for patients.^{7,8}

Hospitals face special challenges in providing continuity of care for patients with complex needs due to an increasing number of specialized units, numerous professions and specialists involved in treatment and care, and that health-care providers work in shifts.^{4,9} These challenges apply to coordination within and between hospital units,⁹ as well as transitions between service levels and long-term collaboration among multiple actors and services.¹⁰

Various models have been introduced in hospitals to secure efficient coordinated care for patients. Examples are clinical pathways,¹¹ care pathways,¹² process-oriented redesign,^{10,13} case management,¹⁴ advanced nursing roles with extended coordination responsibility,^{15,16} and formal agreements on collaboration.¹⁷ A Norwegian approach has been to assign health-care providers within clinical staff a personal responsibility for the development of individual care plans and for taking on a coordinator role to guide the patients through a fragmented health-care system.¹⁸

Studies of coordination work in hospitals have focused on different aspects, such as daily coordination of resources and processes to enhance the continuity of work and treatment of patients across shifts and professions,^{9,19} distribution of responsibility,²⁰ challenges related to design and performance of particular coordinator roles,^{15,16,21} the dynamics of collaboration in coordinating processes,^{22,23} handoffs, information-sharing or the use of care plans to secure transitions,^{24–26} barriers and facilitators to coordinated care,^{15,27,28} or on how to handle multimorbidity or complexity.²⁹ These studies either focus on the needs of a defined patient group,^{22,24,30} a particular context with defined collaborating partners,^{28,30} or have evaluated the implementation of new organizational models with defined coordinator roles.^{15,16}

Hospital patients' needs are diverse, and hospital units vary when it comes to tasks and aims, staff, and organization. For successful development and implementation of coordinators to ensure continuity of care for patients with complex needs in various contexts, there is a need for enhanced knowledge about ongoing coordination practices. However, we have not identified studies covering various hospital contexts, in terms of patient groups and roles, of how health-care providers in their everyday practice define and experience coordination activities aiming at continuity in the health-care trajectory for patients with complex needs.

The aim of this study was therefore 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.

Methods

This qualitative study employed semi-structured individual, duo, and group interviews with health-care providers from different hospitals, departments, and professions throughout Norway. The study includes experiences of health-care providers with formal care coordination responsibility as well as experiences of clinicians taking on coordinator responsibility. The interviews were conducted in the spring of 2015.

Setting

Norway has a publicly funded health-care system mainly free of charge for patients at the point of service. Specialized health care is run and owned by the state.¹⁷ Primary health and social care is organized and financed by the municipalities. Similar to other Western countries,^{1,18} Norway has implemented national reforms aiming to reduce fragmentation of services.³¹

In 2001, patients with complex needs gained a legal right to an individual care plan coordinated by one of the service providers.³² In 2012, the hospitals were legally required to appoint a patient care coordinator for patients with complex or long-term needs of services to secure continuity of care in the individual patient trajectory.³³ This applies to patients needing services from two or more different units and professions over time, independent of medical condition(s) or from which hospital departments the patient receives treatment.³⁴ It is statutory for each hospital to have their own Coordination Unit that is responsible for implementation and development of these arrangements.

Interviewees

Given the exploratory aim of the study, we used purposive sampling to include health-care providers, from different hospitals and different departments, with broad experience in coordination activities aiming at continuity of care for patients with complex needs. We sought out interviewees both in designated or formal coordinator roles, as well as interviewees with coordination experience from taking on coordination responsibility in clinical work without having a designated mandate. Additionally, we sought variation in the interviewees' workplace, tasks, profession, experiences with care coordination, and in the patient groups within their responsibility. The coordination activities in focus were activities directed at patients with

complex or long-term needs of services from different units and professions with a variety of medical conditions, identical to the target group for the legally required patient care coordinator. We aimed at representing a variety of settings where this new universal coordinator role was to be implemented, as well as health-care providers in different work roles and with varied professional background who might be candidates to fill this new statutory coordinator role in hospitals.

The recruitment was carried out as a stepwise process, including one hospital at a time to ensure variation in the interviewees' experiences regarding care coordinator roles. A nationwide survey conducted by the first author (AH) in August 2014 on Norwegian hospitals' implementation of patient care coordinator roles was used as a basis to select the hospitals for this study. Each hospital's Coordination Unit was asked to identify candidate interviewees from their hospital based on given criteria. From two of the hospitals, we requested interviewees among clinical staff from various departments with the desired experience; from the other four hospitals, we requested designated coordinators. The Coordination Units forwarded our request to department leaders. The leaders then identified candidate interviewees and conveyed an information letter presenting the study with a consent form included. The Coordination Unit returned the consent forms with contact information from those willing to participate. Candidate interviewees were then contacted by AH. All approached candidates, except one, agreed to be interviewed.

Data collection

Sixteen health providers were interviewed, seven individually, two in a duo interview, and seven in groups. The interviews were semi-structured, audio recorded, and transcribed verbatim.

Providers in clinical positions from different departments in the same hospital were interviewed in groups. Group interviews were chosen in order to facilitate reflections on coordination work in different settings between the clinicians. These interviews were inspired by focus group techniques with the interviewer in a moderator role.^{35,36} The interviewees in designated coordinator positions were interviewed individually to allow for going more into details about the particular coordinator role. Two of the candidate interviewees were sharing a designated coordinator position. When asked, they both wanted to participate in the study. They suggested to be interviewed together, explaining that they had different professional background and had experiences from different aspects of the coordinator role. This duo interview followed the structure of

the individual interviews. AH conducted all the interviews with DG participating in the first group interview. The interviews took place at the interviewee's workplace, except for the individual interviews of the two coordinators on system level (see Table 1), which were conducted through telephone. The average time for the two group interviews was 85 min (70 to 100 min) and for the seven individuals and the one duo interviews was 55 min (41 to 83 min).

The following guiding questions were applied for both types of 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? Reflection notes were taken immediately after the interviews.

Analysis

The analysis followed the four steps of systematic text condensation (STC).³⁷ STC is a procedure for thematic cross-case analysis that is inspired by Giorgi's psychological phenomenological analysis. However, STC is also recommended when the approach is descriptive as in this case, aiming at presenting the interviewees experiences as they express them — not searching for an underlying meaning of what they present.³⁷

To gain an overall impression and formulate preliminary themes (step 1), AH listened through, proofread, and read all the transcripts. The coauthors read the two most comprehensive transcripts. Based on this, 11 themes were initially formulated. Through discussions between all authors, these were revised to seven.

In step 2, units of meaning — data elements from the interview transcripts relevant for elucidating the research question — were coded into groups subordinated to these seven themes by AH using the data software NVivo11.³⁸ A comprehensive collection of quotations from all interviews, structured according to the seven themes, was read by the coauthors. The themes and code groups were then discussed and negotiated repeatedly in the author group resulting in a reduction to three themes: knowing what is the objective of good coordination, legitimacy for the coordinator role and coordination work, and having access to the necessary coordination resources.

In the third step, the meaning units in the code groups within each theme were condensed into an abstraction containing the content of the included meaning units. This text was used as a foundation for refining the themes, and constituted a starting point for the presentation of the study results. Quotations from the interview transcripts were selected to illustrate the themes.

Table 1. Interviewee characteristics.

Characteristics	Number
Gender	
Female	15
Male	1
Profession	
Nurses	11
Physicians	2
Medical secretaries	2
Social worker	1
Position in relation to coordination work	
Formal coordinator position within established clinical pathway	4
Dedicated coordinator position for defined patient group	1
Dedicated coordinator position on a system level	2
Clinician with coordination responsibility in units where most patients get a personal contact among the healthcare providers (rehabilitation, psychiatry, substance abuse)	4
Clinician taking on coordination responsibility for selected patients	4
Administrative position, leader of department	1
Hospital setting	
Wards	8
Outpatient clinics	3
Centre/ambulatory service	3
Coordination unit	2
Main patient group (n > 16. Some had more than one main patient group)	
Cancer: lung, breast, bowel and rectal cancer	6
Children with complex conditions and rare syndromes	1
Dementia	1
Need of technological breathing assistance	1
Psychosis and other severe mental health problems	2
Severe traumatic brain injury and other neurological conditions	2
Stroke	1
Substance abuse	1
All diagnoses (position on system level)	2
Work practice	Mean (range)
Years since started to work in clinical setting	18 (5-31)
Years since started to work in current department	7 (2-18)

In the final step, we wrote the result section building on the condensates, further refining the themes and the text. The theme headings were revised to cover the final results for each theme. Ultimately, we validated the final text against the interviews.

Results

The interviewees worked in 15 different departments at six different hospitals. Seven worked part time or full time in designated coordinator positions dedicated to an established pathway (n = 4), a defined patient group (n = 1), or with responsibility for coordination in the hospital on a system level (n = 2). Eight were health-care providers who had taken on informal coordination responsibility for patients within their clinical role. One was the leader of a department.

The interviewees presented a diverse range of coordination activities, from follow-up of care transitions or being available as a contact person to implementation of clinical pathways or orchestration of long-term multidisciplinary care across contexts by continuously adjusting care to complex and shifting needs.

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."

Keeping one step ahead

The most prominent common feature defining the interviewees' coordination activities was to plan for the next step, being in front of things, anticipating expected progression of the illness or disability, and trying to predict the patients' future needs for services and support.

I must sort of keep one step ahead to get the measures in place in time. That is how we can make them feel safe. (Specialized nurse in palliative team)

The goal of the coordination activities was mainly said to be providing continuous support that was adapted to the patients' anticipated needs. Several told of how they worked to enhance continuity for the individual patient by mono- or multidisciplinary teams working together around the patients.

For particularly vulnerable patients, establishing long-lasting relations with one or a few health-care providers was emphasized as important. Due to the organization of the staff or to shifts and conflicting responsibilities, however, it was said to be demanding to take on personal responsibility for the continuity around one specific patient in many of the represented departments, both during hospital stays, and especially for following admissions or consultations. Some of the interviewees, also those without designated coordinator roles, took on responsibility as contact persons for patients between hospital visits when they saw this as necessary. This typically concerned patients with

progressive conditions in contact with outpatient clinics or ambulatory services. One nurse talked about how she arranged that selected patients with particularly severe disease and functional impairments at regular intervals met an experienced specialized physician who knew them well. She told that she facilitated maintaining the patient's relationship with one doctor, while at the same time allowing experiences with these patients for junior doctors in training.

Establishing fixed points of contact in primary care was reported as particularly important. Nurses working in outpatient clinics with dementia and incurable cancer described how they prioritized establishing relations between patients and central providers in primary care at an early stage when expecting increased needs of services.

(...) we are in contact with the "dementia coordinators" [in the home care services] so that they can be prepared and plan ahead. (Nurse, geriatric outpatient clinic)

A nurse in cancer care told how she sometimes had to negotiate with the patients about contacting the cancer care coordinator in the municipality when she considered the burden of the worsening health situation too heavy for the patient and his family. She referred to examples where both the patient and family were reluctant to accept the need of receiving help at home, experiencing this as conflict between ensuring continuity and the patient's or the family's hopes and understanding of the situation.

The variation in the scope and extent of the coordination among the interviewees influenced the area of responsibility they took on regarding keeping ahead. While some limited their coordination activities to the primary responsibilities of diagnostics and treatment in the units where they worked, others took care of patients' coordination needs in a broader perspective and included an extended period after discharge. One working with substance abuse treatment expressed the need of providing a "security net" if the patient decided to leave the hospital before follow-up was organized.

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 large part of the coordination activities related to keeping ahead concerned safe transitions and facilitating collaboration between providers across units and sectors. They described establishing contact, securing information transfer, sharing competence, monitoring

planned events, and establishing arenas for mutual multidisciplinary planning to create good solutions for the patients. Nevertheless, several interviewees reported reduced opportunities for coordination between the hospital and primary health care. They described how collaborating meetings were replaced by electronic messages. The electronic messages were said to be of great help, but had reduced the personal contact, which was a cornerstone for some interviewees in getting future measures in place. Collaborative meetings, where also the patient and family participated, were found to give more creative solutions and better tailoring of the services around the patients. Some also mentioned these meetings as an opportunity to supervise or educate primary health-care personnel when patients had special needs or advanced equipment, or to support them in roles that could be lonely and demanding.

It is usually very fruitful to gather around the same table, as we often find alternative and better solutions. (Psychiatric nurse, rehabilitation department)

The interviewees also focused on planning, organizing, and monitoring of the multidisciplinary work to secure transitions between units and providers within the hospital. They told of coordinating the teamwork around the patient in a psychiatric ward, conveying information and following up when the patient needed assessment or treatment from different departments, monitoring and adjusting patients' processes through a planned pathway, and educating and orchestrating personnel prior to admission of severely disabled patients needing advanced equipment.

Identifying and activating resources for coordination

Most of the interviewees told of constraints in available resources, especially in capacity, competence, and work organization needed to perform coordination activities. However, they exploited available resources to make coordination activities possible when considered necessary. There was broad variation in what the interviewees talked of as resources. These included organizational structures on different levels, access to relevant follow-up services, the availability of personnel with desired competence, and the freedom to work in a way they considered appropriate to ensure continuity for their patients.

The availability of resources for coordination work varied relative to the interviewees' role and work context. Those coordinating the standardized clinical pathways for cancer told of how they primarily coordinated the planned stream of events in the defined process for their patients. Moreover, how they extended their

responsibility and made room for exceptions from the standards when they considered that individualized coordination was required to meet individual patients' needs. They presented how they, by virtue of their role, had a voice in the multidisciplinary meetings where the decisions were made regarding the course of treatment for the patients. Additionally, they held a position where they knew the routines and the stakeholders both in their own and in collaborating departments, being able to activate additional resources when needed. This was contrasted by one interviewee with the responsibility of coordinating early stage rehabilitation according to an ideal pathway, but where there was no pre-booked access to rehabilitation services after the initial phase. These services had to be negotiated and were source of considerable frustration for the coordinator, as there had been a gradual downscaling of the needed rehabilitation services both in the hospitals and in the municipalities.

The reduced length of stay at many hospitals increase the pressure on the specialized rehabilitation services. A coordinator responsible for securing access to rehabilitation in such a situation will not be able to succeed. (Specialized physician, coordinator early phase of rehabilitation after brain injury)

Some of the interviewees were working in units with established routines for multidisciplinary teamwork, where a designated team of providers is created for each patient based on the patient's needs. Their way of working included the patients' participation in defining needs, formulating goals, and designing the services, often with the use of different type of individual treatment plans or rehabilitation plans for the hospital stay or for a longer period. The patients get a contact person in the team during hospital stay with a "secondary contact" to take over if the contact person works in shifts or is absent. Often other team members are also prepared to take on coordination or collaboration tasks. The interviewees spoke of how they utilized or extended their unit's way of working in their collaboration with internal and external colleagues to meet the patients' needs.

Some patients have recurrent hospital stays. If they have a coordinator in primary care, and the stay is not too long, we try to act as one team together with the primary care team as long as they are in the ward. (Nurse, psychiatric ward for young patients with psychosis)

Those without established pathway structures or organized multidisciplinary working routines to lean on had to negotiate solutions per individual cases. For them, it

was particularly important that they had the autonomy to manage some of their working time, as well as having access to a relevant collaborating network and authority to activate this. One had a designated position in a somatic department with responsibility for severely disabled patients. For this group, the need for individual coordination was solidly anchored with the management.

When you have a designated coordinator role like me, you are more free and flexible to make appointments. You are allowed to visit patients at home and you can admit them to hospitals outside of the planned admissions. (Coordinating nurse for severely disabled patients)

In contrast to this, the majority experienced the need to create the opportunities for taking on coordination activities in addition to their other duties. Several interviewees described how they performed resource-consuming coordination work without resources set aside for this type of work. Some told of being flexible and creative in establishing acceptable individual solutions when coordination resources were scarce. For example, by ensuring transfer of responsibility to a colleague or a team in another unit or sector or by orchestrating collaboration between providers from different departments or sectors in a team around the patient.

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)

Another example was given of a situation where the hospital did not let go of the coordination role for a patient with complex needs at discharge because no one in primary health care would take over the overall responsibility. In this case, coordination of the follow-up across sectors, services, and professions over time was made possible by using the department's psychiatric nurse as a coordinator because of her free-standing position in relation to the daily tasks in the ward. Situations where the interviewees were able to extend their responsibility so far without designated coordination resources, however, were few and concerned special cases.

Coordination activities may challenge the established division of tasks and responsibilities, especially when some providers extend their responsibility. This can imply transcending the boundaries of other providers. The interviewees told about being sensitive

and responsive in the interplay with other providers in these processes. Some also emphasized the need of having autonomy and flexibility anchored in the leadership when extending their role across boundaries.

The most important is that it is accepted that others can come in and make decisions [about what needs to be done in a patient's trajectory]. It feels strange to step over the other providers' border. (Coordinator, nurse, cancer pathway)

Justifying the priority and quality standards of coordination work

Both the interviewees working in designated coordinator positions and those in clinical positions without designated coordination resources or mandates told of how they often expanded their role to take care of what they understood as the patients' needs for continuity support. They used various arguments to justify the scope and extent of their coordination activities and the quality standards they set for this work.

The interviewees in formal coordinator positions primarily referred to guidelines, quality, and patient safety to justify why they went further than their coordination mandate.

In the national guidelines for patients with long-term mechanical ventilation, specialized health care is given an extended responsibility for following up the patients also between hospital admissions. (Nurse coordinator, severely disabled patients)

The physician, who organized joint specialist consultations without having dedicated resources, justified how and why he was doing this with adherence to international guidelines for the present condition. He also told that he aimed to ensure the quality of treatment and enhance the efficiency and use of time for the patient and his family. Moreover, he added the importance of developing and keeping competence on this particular condition for himself and his colleagues.

Some justified their extended coordination responsibility with arguments about the complexity in the patients' situation: the severity or expected progression of the illness, disability, or dependency of technical equipment, demanding life situations, or needs of health care from many sectors or units. Furthermore, the interviewees justified their own involvement arguing that they possessed valuable competence of need for the patient, that they had known the individual patient over time or that they had a special knowledge of the condition, treatment, and health service organization from which the patient needed services.

I am chief physician here, and in charge of the treatment. 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 phase of rehabilitation after brain injury)

Several pointed at the importance of contributing to patient trust when arguing for their priority of coordination activities. They argued that predictability, in terms of knowing who is in charge, what will happen next, and who to contact, enables the patients to handle more challenges at home. They referred to experiences of reduced anxiety for the patients, reduced frequency and length of hospitalizations, and enhanced quality of treatment.

The fear is what leads to many admissions I believe. Feeling insecure and not taken care of – one will be admitted to hospital more easily than if one feels safe at home. (Nurse, outpatient clinic, patients with lung cancer)

Discussion

The common feature of the studied coordination work was to "keep one step ahead". The scope of the interviewees' coordination activities varied from transferring follow-up responsibility to another provider, via implementing a planned pathway, to organizing long-term multidisciplinary teamwork adjusted to complex and shifting needs across care contexts. All interviewees presented practices where they strived to balance the perceived coordination needs of the patients and the opportunities in their contexts. The interviewees told of how they employed their experience, knowledge, and sensitivity both when defining their patients' needs and when searching for resources that could be allocated to orchestrate care coordination. While some justified the coordination activities by referring to mandated roles, planned pathways or guidelines, others focused on complex patient needs, multidisciplinary working routines, care quality, or on their own knowledge and network.

This study comes with a few limitations as well as strengths. We aimed at investigating a variety of coordination work, through the experiences of health-care providers, in contexts relevant for implementing the new statutory care coordinator role. The recruitment strategy enabled identifying a diversity of experiences with care coordination directed at ensuring continuity for patients with complex needs. All participants had extensive experience with coordination work, thus

representing high specificity of experiences. Our approach permitted identifying both commonalities and variation of coordination work across settings in hospitals. However, the recruitment process might have favored interviewees standing out as especially active and engaged in care coordination, thus biasing our sample toward those with greater autonomy than most. Eleven out of sixteen interviewees were nurses. This may reflect that coordination responsibility is more closely aligned with nursing than other professional roles. With a broader professional diversity, we might have captured a wider variation of coordination activities in hospitals.

While the individual interviews allowed detailed descriptions of one coordinator's role and context, the group interviews provided reflections around coordination activities between health-care providers in different roles and contexts. This combination of interview types contributed to rich data, as well as increasing the diversity of coordination activities presented. There is, however, a trade-off between width and depth in qualitative cross-case studies. By applying the concept of information power,³⁹ we argue that the design and size of our sample meet the requirements considering our explorative study aim. A limitation is that the analysis is based exclusively on interview data. Field observations could have enriched our data and strengthened our findings. However, coordination activities cannot be easily observed since they take place intermittently, in various places, and include merely a selection of the patients in the wards or units. It would also have strengthened the quality of the study if the interviewees were given the possibility to review and to give feedback on the interviews transcripts and findings.

Keeping one step ahead, by taking a future perspective on the patients' needs, was the central approach in the coordination activities conducted by the interviewees in our study. Both those in designated coordination positions and clinicians taking on coordination responsibility told of how they extended their regular roles and responsibility to ensure continuity for their patients. Previous research has highlighted the extended role as a characteristic of being a care coordinator.^{15,16,40} Bradway et al.¹⁵ describe nurses going "above and beyond" their role and responsibility and doing whatever was necessary to provide continuity for the individual patient in a study of implementing a new care coordinator role. However, the clinicians taking on informal coordination roles did not tell much about discussions with leaders and colleagues to make care coordination possible. The way they described their role in this type of work is similar to how hospital nurses conceptualized clinical autonomy in a Canadian study:⁴¹ Namely, as the ability to

accomplish patient care goals through interdependent work as part of the health-care team where their knowledge and skills were recognized, valued, and acknowledged by the collaborators.⁴¹

Further, the interviewees in our study also described several constraints related to "staying in front of things." Other studies have found that providers in hospitals experience challenges in negotiating a coordinator role and in applying a comprehensive patient-centered perspective when coordinating what they consider being of importance for their patients.^{21,27,28} In a Danish study, the nursing staff in an acute medical department felt that their professional values of providing continuity of care were overpowered by the medical and episodic focus.²⁸ Our interviewees expressed, on the other hand, that they managed to create opportunities for patients they considered being particularly in need of continuity support. Furthermore, we found that our interviewees adjusted the continuity ambitions on behalf of their patients to what they considered doable regarding which types of continuity⁴² and which degree of integration⁴³ they aimed at.

The Norwegian legal requirement for hospitals to appoint personal coordinators to secure continuity in the care trajectories for patients with complex long-term needs³³ has not led to the anticipated results.⁴⁴ Other studies from Norway report that providers have been reluctant to adopt the personal responsibility for individual care plans and ensuring continuity for patients according to laws and regulations.^{17,32} We found that there were providers who did take on personal responsibility for coordination aiming at continuity of care for selected patients, which in many ways were similar to the new statutory role. However, none of the interviewees in our study described their coordination activities as carrying out the statutory care coordinator role.⁴⁵ Our interpretation is that the coordination responsibility that the interviewees in our study took on was defined and delimited by the providers themselves within the opportunities and constraints in their working context. Thus, the scope and extent of the coordination activities was developed through a bottom-up process, resulting in personal and context-sensitive coordinator roles.

The expectations toward the statutory patient coordinator role, as it is described in Norwegian policy documents, are extensive but vague when it comes to aim, scope, target group, and responsibility.⁴⁵ Miller et al. has studied the implementation of an ambiguous care coordinator role from the perspective of nurse role holders.²¹ They concluded that when there is role ambiguity, those having the role need information, rules, or prototypes to fall back on to make sense and get guidance. Doessing and Burau point out that support of

coordination initiatives must be on both organizational, professional, and managerial level.²⁹ Furthermore, as referenced in the introduction, there are several approaches to improve continuity for hospital patients.^{11–14} While some coordination measures are visible and established in organizational structures, procedures, or formalized roles like case managers¹⁴ or care coordinators,³⁰ much of the coordination activities identified in our study is either performed outside such structures or goes beyond them.

The interviewees described how they continuously orchestrated individualized solutions within the frames and opportunities of current practice.

They were negotiating continuity for selected patients by knowing “the name of the game.” This is in line with how Allen in a study of hospital nurses’ organizing work¹⁹ found that the nurses had a “trajectory awareness” that they applied in their management of care. Moreover, this was often invisible work dependent on skills that were built over time and in the current context. Based on our study of health-care providers’ coordination experiences from various hospital settings, we suggest that there is a need of flexible support and available infrastructural resources adapted to the providers’ needs and to the current hospital contexts to enhance coordination activities in order to secure continuity of care for patients with complex needs.³³

A common feature of coordination work in hospitals across patient groups and settings was found to be that health-care providers involved “keep one step ahead” to create continuity of care for patients with complex long-term needs. In doing so, they maneuver in the systems by utilizing structural resources such as work routines, team organization, or planned pathways as well as exercising clinical autonomy to extend their role, allocate time, and employ appropriate ways of working.

To succeed with efforts to reduce fragmentation of services for patients with complex needs, there is need for improving visibility and acknowledgement of ongoing coordination work that goes beyond established workflow routines and clinical pathways.

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Author contributions

AH conducted all the interviews individually, except from one group interview that was conducted together with DG. AH did the coding. The analysis was a joint process between all authors. AH drafted the manuscript. All authors

contributed to the subsequent manuscript drafts and approved the final manuscript.

Availability of data and materials

The datasets generated during and/or analyzed during the current study are not publicly available due to restrictions in consent from interviewees.

Declaration of conflicting interests

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Ethics

The study was approved by the Data Protection Official for Research at the University Hospital where the project is organized.

Research team—reflexivity

The first author (AH) is a PhD student, educated as an occupational therapist. Prior to the study, she worked in an advisory position supporting Coordination Units in the hospitals within one health region in planning and implementing the new statutory care coordinators for patients with complex or long-term needs of care. Hence, she had access to a network of Coordination Units in Norwegian hospitals. These units were approached with a question of contacting clinics in their hospitals to recruit candidate interviewees for the study. AH did not know the interviewees, and had no working relation to any of them. The coauthors are experienced researchers in the field of health service research with professional background as psychologist (DG), physician (GB), and sociology (AS).

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Paper III

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RESEARCH ARTICLE

Open Access



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

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Abstract

Background: Person-Centered Integrated Care (PC-IC) is believed to improve outcomes and experience for persons with multiple long-term and complex conditions. No broad consensus exists regarding how to capture the patient-experienced quality of PC-IC. Most PC-IC evaluation tools focus on care events or care in general. Building on others' and our previous work, we outlined a 4-stage goal-oriented PC-IC process ideal: 1) Personalized goal setting 2) Care planning aligned with goals 3) Care delivery according to plan, and 4) Evaluation of goal attainment. We aimed to explore, apply, refine and operationalize this quality of care framework.

Methods: This paper is a qualitative evaluative review of the individual Patient Pathways (iPP) experiences of 19 strategically chosen persons with multimorbidity in light of ideals for chronic care. The iPP includes all care events, addressing the persons collected health issues, organized by time. We constructed iPPs based on the electronic health record (from general practice, nursing services, and hospital) with patient follow-up interviews. The application of the framework and its refinement were parallel processes. Both were based on analysis of salient themes in the empirical material in light of the PC-IC process ideal and progressively more informed applications of themes and questions.

Results: The informants consistently reviewed care quality by how care supported/ threatened their long-term goals. Personal goals were either implicit or identified by "What matters to you?" Informants expected care to address their long-term goals and placed responsibility for care quality and delivery at the system level. The PC-IC process framework exposed system failure in identifying long-term goals, provision of shared long-term multimorbidity care plans, monitoring of care delivery and goal evaluation. The PC-IC framework includes descriptions of ideal care, key questions and literature references for each stage of the PC-IC process. This first version of a PC-IC process framework needs further validation in other settings.

Conclusion: Gaps in care that are invisible with event-based quality of care frameworks become apparent when evaluated by a long-term goal-driven PC-IC process framework. The framework appears meaningful to persons with multimorbidity.

Keywords: Person-centered care, Delivery of healthcare, Integrated care, Health service research, Multimorbidity, Long-term conditions, Evaluation research, Care process, Goal attainment, Continuity of care

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Background

For persons with multiple long-term conditions and complex healthcare needs, diagnosis centered, fragmented and reactive care is believed to cause a poorer care experience and worse outcomes [1–3]. Our current healthcare system owes much of its success to a reductionist and specialized approach where we understand each diagnosis by its cause and treatment. As a result, a person with multimorbidity will receive care from a multitude of specialists who either cater to a part of the body (e.g., neurology) or provide one type of treatment (e.g., surgery). However, patients experience care within the context of their life and not through the professional lens of a diagnosis or treatment modality. For instance, persons with multimorbidity report how care involving multiple providers induces the experience of being an incidental carrier of many diagnoses or being a messenger between diagnosis specific professionals. They report confusion amidst numerous single disease treatments, which are rarely reviewed together [4–6]. In the context of multimorbidity, it is therefore reasonable and necessary to study the entire set of healthcare activities generated by all care providers within the larger frame of the person and his/her life project.

Person-centered and integrated care

Multimorbidity guidelines increasingly identify both Person-Centered and Integrated Care (PC-IC) as central components of quality of care [7–10]. A PC-IC goal-oriented approach also has strong traditions in fields that commonly work with patients over the long-term, such as rehabilitation, geriatrics and General Practice [11, 12]. A PC-IC process is believed to enhance both technical and patient-experienced quality of care to produce the triple aim [13] of improved care experience, health, and function, as well as cost-benefit ratios [14–21]. Despite the widespread agreement of the desirability of PC-IC, progress in this area seems to be slow [5, 22–25]. The lack of progress may be due to the unclear conceptualization of what PC-IC is, and absence of evaluation tools that support improvement efforts. The literature on PC-IC is awash with overlapping and conflicting concepts and terminology [26–29], making it challenging to develop united frameworks that may structure patients' experiences of care quality. PC-IC represents quality dimensions that are best assessed by the patient. Both person-centered care and integrated care concepts pertain to how the multi-faceted care system creates a seamless, personalized pathway that addresses the person's needs, values and preferences as they develop over time.

To come to grips with this complexity, we have simplified the overall concept of patient-experienced quality of care using PC-IC as a starting point. We were inspired

by; the practice of goal-oriented chronic care [11, 12], our knowledge of theoretical concepts and models relevant to chronic care [30–33], principles for goal-directed process design [34], and experiences from our previous research on goal setting [35]. The result is a 4-stage goal-oriented PC-IC cyclical process.

The PC-IC cyclical process

- 1) Goal identification: Our starting point is a goal-oriented definition of PC-IC, where the person's overarching goals drive decisions about care [31, 35]. The rationale for the goal-oriented approach is simple: A person perspective requires a strong element of care coordination to ensure that all contributors work towards a common goal. It is only the person, both in ethical and legal terms, who can legitimately identify what the overarching goal should be. It is not enough to be respectful and attentive, nor is it enough to involve and engage the person. PCC is a matter of transferring power to whatever the person has identified as his/her overarching goal. Together with the person, the professionals make this the real driver for decision making [35]. Some patients may not wish or be able to participate in such a process. Care professionals may then have to seek advice from the person's significant others or make intelligent guesses about "what matters" to the person. The point is to make the overarching goal(s) for care explicit. If they remain unspoken, participants lose the "coordinating effect" of a common goal. Also, mismatches between patient preferences and health care assumptions may be missed by both patients and professionals.
- 2) Care planning: The personalized goals are used to identify the multidisciplinary team needed to assess the patient's health issues. Subsequently, the team produces a comprehensive care plan aimed at goal attainment [7–10]. The plan should as far as possible be evidence-based [9] and should support health literacy [36], patient involvement and self-management [14]. The plan should identify roles, tasks, and responsibilities, including those taken on by the person and his/her significant others, to ensure seamless care.
- 3) Care delivery: The team, including the person, is then responsible for care delivery according to the plan. Loyalty to the plan is essential, as a plan that is not carried out, or a derailed plan will not produce the desired outcomes. Included in care delivery is the regular review of goals, plan and goal attainment whenever needed.

- 4) Goal evaluation: Patient-driven evaluation of goal-attainment, is the last of the four stages of the cycle. Goal evaluation serves as feedback to all contributors in the seamless care process. The result should be documented and linked back to goal adjustment and learning for the next cycle, in line with complexity and quality improvement theory [12, 37, 38].

We have called the timeline map of all care events for one individual the “individualized Patient Pathway” (iPP). The iPP borrows the “pathway” term and the timeline from the “care pathways” concept, which maps out events designed to manage a single condition across providers [39]. A multimorbidity iPP will thus represent the aggregate of all care delivery meant to care for the person’s ensemble of health issues, organized by time. The ideal iPP follows the rules similar to project management: Participants share clear goals. Plans detail sub-goals and sub-tasks. The resources needed to achieve goals are identified and allocated. Goal attainment indicates success. Finally, the project adjusts goals before the cycle starts over.

Knowledge gaps and aim for the study

Many authors have already tried to make quantitative instruments that evaluate the patient care experiences in light of chronic care ideals [1, 40–45]. However, the underlying assumption in these instruments is that the care event is the basic unit of interest. We have not found evaluation frameworks that make the long-term iPP the unit of study. When the process, as opposed to the event, comes into focus, the goal of the process becomes the success criterion. Previous qualitative studies exploring iPP experiences exist [5, 46–51], but none of these compare care to an ideal. To the best of our knowledge, reviewing the iPP experience through the “lens” of the above PC-IC framework is unexplored.

Norway, like most other western nations, is pursuing large-scale transformation towards PC-IC, which has been an explicit health policy since the late 1990s [52, 53]. This focus has become even more prominent with the current administration [54]. The Norwegian healthcare system has comparable medical outcomes to other western healthcare systems [55]. A systematic exploration of a new method for PC-IC evaluation of the iPP in a Norwegian context should therefore be of general interest.

Our primary aim was to explore how the PC-IC process ideal might be useful as a guide to capture iPP quality and then apply, refine and operationalize this ideal into a quality of care framework. Our research questions were:

- What can we learn about the patient-experienced quality of care by the application of a PC-IC ideal to 19 iPP experiences of persons with multimorbidity?
- Which lessons from the empirical analysis can contribute to the refinement and operationalization of the PC-IC ideal into an evaluation framework?

Methods

Our work is a qualitative evaluative study of patient-experienced quality of care relative to PC-IC ideals for chronic care, conducted within a pragmatic interactionist tradition [56–58]. While we acknowledge that central concepts of disease, health, and care are socially constructed, we treat these constructs as stable and familiar enough to illuminate how patients evaluate their care [56]. We applied the PC-IC ideal as a structuring framework to the iPP-experience of 19 strategically selected individuals ad modum Ritchie [59]. An outline of the research process is given in Fig. 1.

Material

Setting, informants, and recruitment

We aimed to include informants with a wide range of experiences with long-term health challenges. Cancer patients in active treatment represented experiences of a severe long-term life-threatening condition with a clear starting point and treatment options. Cancer survivors with ongoing sequelae represent patients with considerable everyday health challenges, but fewer treatment options. Finally, persons with various long-term conditions and complex needs served to examine similarities across diagnoses. We refer to study participants as either persons, informants or participants. The term “patient” in this text, refers to the smaller part of a person’s life when he/she is in direct interaction with a healthcare provider.

The material incorporates data from 19 persons with long-term, complex care needs from two studies:

Study 1: Thirteen persons (age 48–74) with cancer under active treatment, or cancer survivors with long-term sequelae, taking part in the Connect study (online cancer support) [60], were recruited by the local cancer nurse. One participant died, and one withdrew leaving 11 persons in the project.

Study 2: In the Troms-Ofoten (TO) study, care providers and patient advocacy organizations purposively selected one person from each of the following eight groups to ensure diversity regarding condition(s), context and demography. 1) Frail elderly with an episode of emergency care 2) Diabetes 3) Cardiovascular/pulmonary disease 4) Mental health issues 5) Cancer 6) Child with multiple disabilities 7) Mental health and substance abuse 8) Postoperative care. Age 9–76 years. Methods and preliminary results for the TO-study can be found in a Norwegian language report [61] (Table 1).

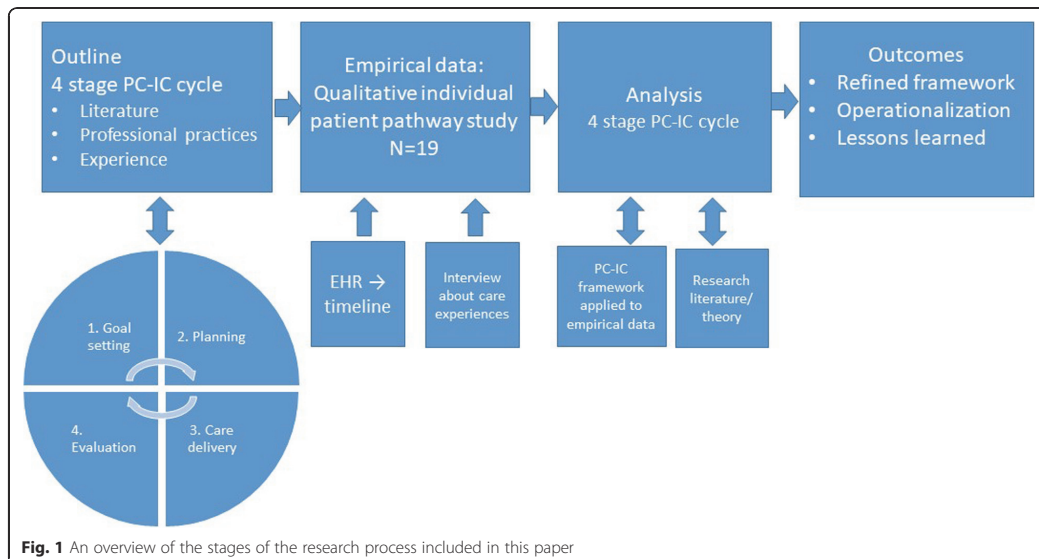


Fig. 1 An overview of the stages of the research process included in this paper

Data collection

All informants filled a questionnaire on their socioeconomic and demographic background.

Timeline of iPP We constructed the iPP timeline of clinical events from the hospital, general practice (GP) and nursing services¹ electronic health record (EHR) from the prior 6¹ or 12² months. We created a table timeline of all clinical events, defined as consultations for diagnostic, therapeutic, or informational purposes. For each event we recorded time, EHR source (hospital, nursing service or GP), type of contact (outpatient, phone, admission), place (geographical, organizational), health profession, the degree of urgency and a short text summary of the main issue

of the event. We produced simple quantitative descriptions (means, median, and range) of pathway complexity normalized for follow up time.

The patient interview We used the iPP timeline as a basis for the retrospective, evaluative interview with each informant. The interviews followed a semi-structured interview guide (see online Additional file 1) which briefly included:

- 1) A shared review of the iPP timeline. We invited the informant to:
 - a. Correct any mistakes. (No corrections made).
 - b. Identify events of importance, along with their reasons for identifying them as such. Follow up

Table 1 Background characteristics and care complexity measures for 19 informants, Norway, 2011–2013

Informant background	N	N	N
Gender	8 males	11 female	
Employment status	7 employed	7 unemployed	1 child/4 pensioners
Living arrangements	3 alone	16 with spouse/children	
Home municipality	14 rural	5 urban	
Care complexity	Mean	Median	Range
# of diagnoses treated per year	5	4	(2–10)
# different health services per year	6	5	(2–12)
# of general practice visits per year	10	7	(1–36)
# of health service visits per year	28	21	(5–132)
# of inpatient days per year	16	4	(0–130)

questions elicited the informants' view of the event's usefulness/satisfaction and the basis for their judgment.

- 2) An evaluation of the whole iPP (not restricted to the timeline) regarding care goals, care plans, involvement in care decisions, experienced continuity of care and support for self-management.
- 3) An evaluation of the Patient Assessment of Chronic Illness Care (PACIC) questionnaire. We thought the PACIC, which builds on the Chronic Care Model, might be useful to capture patient experienced care quality. We therefore added a "Think aloud" session of the PACIC to explore its utility [45, 62]. The PACIC asks patients to estimate to what degree specific care characteristics, i.e., patient involvement, were present over the past six months of care. However, the informants explained that even if care was excellent most of the time, a single unfortunate incident at a critical moment could still have disastrous consequences, threatening the results of the entire chain of care. Furthermore, the PACIC did not differentiate between providers. E.g., care at provider X was always great, but provider Y, which they saw more rarely, was not. In both cases, the PACIC would capture this as excellent care most of the time, which seemed wrong. The first six respondents provided similar feedback. Hence, we omitted the PACIC in the subsequent interviews.

Interviews were conducted in the informant's home, or in an office facility according to informants' wishes by GB/DG (Connect study) in fall of 2011–2012 or GB/AH (TO-study) in 2012–2013. We interviewed the parents of the underage informant (parents views represent only one patient in quantitative descriptions). We transcribed interviews "ad verbatim."

Analyses

Evaluative assessment of the iPPs

Author pairs: 1) GB – AH, 2) GB - DG analyzed the interviews of the TO and Connect data respectively using a methodology recommended for framework development [59]. Each author pair first familiarized themselves with the material and then agreed upon a condensed synopsis with illustrative quotes capturing the salient themes. We mapped these to themes and sub-themes structured by the 4-stage PC-IC ideal.

Refinement and operationalization of the

PC-IC framework

We developed refinements of the framework so that each "PC-IC stage" could be recognized more consistently

across time, place and observers for each informant. Refinements were successively rephrased, merged/split and modified in light of the iPPs as we analyzed them. Refinements consisted of:

- PC-IC Ideal Descriptions: A short qualitative text of each of the four stages, which describes the desired "ideal" iPP attributes, aligned with literature underpinning each stage.
- PC-IC Key Questions: Formulation of open and closed questions designed to assist evaluation of the presence/ absence of desired attributes for each stage. We first formulated questions per case and successively rephrased to a more general form. E.g. Case: "The waiting-time guarantee of max eight weeks has expired, and my symptoms are worse. Why is my case still not prioritized?" => General: "Did patients have to intervene to avoid or correct mistakes because planned/ expected care was not provided?"
- PC-IC Theoretical underpinning: A heuristic list of salient and relevant literature references linked to the ideals of each PC-IC stage.

We extracted the answers to each of the key questions in each PC-IC stage for each informant. We summarized the responses for all cases in a spreadsheet to ensure analytic consistency across informants.

Results

Goals

"What matters to you?"

Most life goals lie outside the scope of healthcare's responsibility. However, when health issues are blocking the way forward towards a life goal, healthcare can be a vital enabler. The task at hand is to explore what the life goals may be, and then translate these into goals relevant for care.

We had already from the outset an understanding of the iPP as a goal-oriented process, and that we could not review PC-IC quality in the context of single visits or services. We nevertheless initially thought we would be considering sets of events defined by a single short-term problem, or a defining event identified as important. However, early in the interview series, we moved from discussing PC-IC in the context of discrete issues and events to discussing the entire iPP for the whole review period. The salience of the long-term goal was evident as informants repeatedly referred to evaluations of care relative to their overarching long-term goals.

One informant praises the care worker for honoring his long-term goal even when the child protection officer had

taken legal steps to restrict the informant from seeing his son on account of his drug abuse.

“(P) Person: I had to choose. Either I choose the booze or I choose my son. (...), it was really a simple choice. But of course, it was also a new experience when I met a person [care worker] who confronted me with this choice (...). It was at this point that I really woke up and saw the severity of my situation. That was when I started changing.” (...).

(I)Interviewer: How did you react to this [the restrictions?] (...)

P: “At first I was truly upset. But when a few more months had passed, I became really grateful. Because, if she had not made these demands, then I would not have made [the necessary] changes.” Male, mental health and substance abuse issues.

The following is an example where a professional and a personal goal clashes in a decision process regarding the discontinuation of a medication the informant had been using for years. The change in treatment hindered the informant's overarching goal: to be a good mother and to cope with her everyday life. The professional was concerned with adherence to professional treatment guidelines. The informant describes the impact on her life:

“A restlessness, agitation. If I were to make a mind map, I would need 5-6 secretaries nonstop. So, sleeping quality is not good. It becomes exhausting in the end. In addition, you never feel quite awake. I passed 3 months or so without [the medication]. And then I went to see her and I told her that it was... I told her that I want the medication back. “Naahh” she said, we had to weigh effects against risks. Then I said: I do not care about risks. I will take that responsibility myself. It is my life. So, she said that if I assumed responsibility myself, it was ok...” Woman, two mental health diagnoses.

However, these overarching goals were often not made explicit by the informant. Sometimes the informant did not verbalize “What matters” directly, but the important matter, i.e. the overarching goal, shines through in the dialogue.

Another informant repeatedly voiced a need to get his driving license back, but we understood why only at the end of the hour-long interview.

“...That is why I now have asked for rehabilitation, but I didn't get any. But, if I had gotten well enough to

get my driving license back, I could have gotten quite a different “circulation” to my life.”

I: Where would you go if you got your license back?

P: “Well, I know this lady. [From earlier, he describes her as someone who cares for him]. She lives in the mountains. I could visit her there.” Male, five long-term diagnoses.

In fact, when we asked informants directly what their goals of care were, some were surprised or puzzled, because goals of care were either too obvious (i.e., my goal is to survive my cancer), or the informant felt that health professionals should set health-related goals. However, shifting the question of goals into; “What matters to you?” gave a richer and more immediate insight into areas threatened by health issues [63, 64].

Two life areas: “To have gainful employment” and “Being supportive of others” were mentioned more often, and with more ardor. Rehabilitation and mental health services (4 persons) did formulate goals of care linked to life areas such as: “Being able to take care of my kids.” Other more biomedically oriented services did not mention life area challenges in the EHR, nor did patients expect this.

Biomedical goals

“What matters” was often, but not always a life-concern. It could also be a bio-medical issue, especially when the informant had experienced difficulties negotiating this as a legitimate issue with the care system. The informants did not focus much on other overarching biomedical goals which they felt were self-evident. Nine of the 19 informants had disagreed with healthcare professionals regarding the need for a diagnostic investigation, treatment or information at some point during the observation period. Informants reported that they needed to “stress the system” to be taken seriously.

“If you don't shout and scream then nothing will happen. (...) I have been incredibly lucky. All I can say is if I hadn't been admitted to the “X-clinic” if I had gotten a stroke or a heart attack, I would have been dead now. I pestered them and elbowed myself into the hospital. I nagged and pleaded to be admitted. And the general practitioner, he admitted afterward that he didn't think it [my condition] was as serious as it actually was.” Male, coronary vascular disease.

These experiences caused informants great distress and feelings of helplessness. The informants described these as open disagreements, but providers reported

only one of these cases in the EHR at the time of the disagreement. The informant's version was, however, confirmed in the EHR later in six of nine instances.

Goals for self-management

Eight of the informants had received some support for self-management in their iPP. Nine expressed further needs for self-management support regarding their medication, support for physical exercise and training, diabetes follow up, stoma care, lymphedema care, benefits and support opportunities from social care including adapted employment, social skills training, and anxiety management. Lack of necessary arrangements and support for physical exercise/therapy, which is in the grey zone between self-management and treatment, evoked quite strong emotional responses in some participants. Again, mental health and rehabilitation services differ positively from the other providers in that they systematically document self-management support.

Plans

The care plan

Informants understood the concept of a “personal care plan,” and 15 of 19 felt that this would have been useful, but they did not expect such a plan to be personalized (e.g., be adapted to their circumstances or priorities). Participants knew what was going to happen in the short term for single diseases such as cancer, cardiac arrhythmia and heart failure where a routine follow up plan was in place. Long-term planning of the iPP, including self-management support and proactive management of current or likely future health complaints, was not a focus for informants. Nor did professionals mention it in the EHR.

The informants judged the care delivery by the system's loyalty to the plans and expectations they had been given. This informant based his expectations on the care planning process:

“A great doctor admits me, (...). He says that there are so many issues to deal with here. We will look at your blood pressure first, then the “fibrillation.” Yeah – then we will look at your stomach, and then let all the rest wait until afterward. (...) Nahhh [they] didn't look at my stomach. I thought it was a great plan he made. Dealt with one issue at a time, [but] then I was given some tablets, then I got better. (...) I was not done with all that either [exercises], because I could have improved even more. That is when they sent me home.” Male, five long-term diagnoses.

However, of the four persons with a written plan, three were unhappy. One informant described the plan as

inflexible and feared to lose her right to treatment if she asked for personalization. The two others said that since the plan was not implemented, it was not useful.

“I: Do you experience that there is coordination support for you?”

“P: I do not feel there is. I feel it is quite random. When the meeting arrives: Oh, now we are like “formal”, and now we are supposed to make “The Plan”. I get the notes from the meeting where it says what we are all going to do. However, what's done is not always the same as what the note says. There is not really anyone who keeps tabs on anything. (...) If I don't make it start, then things tend just to die out. And it is exhausting. I am actually the coordinator in all this. (...) That's the point isn't it, with seven persons in a team? It's that they should give you feedback, and that they should be there in their domains and have completed this and that until the next time.” Male, mental health and substance abuse issues.

Shared decision making

Involvement of patients, both in relation to the choice of interventions and tailoring of care to a personal context, was hardly mentioned in the EHR. Yet, five patients described consultations where they were actively involved in decision making, two in mental health services and three cancer patients. The other 14 informants did not experience this, nor did they expect it.

Interdisciplinary review

Several of the 14 participants with more than one long-term diagnosis recognized a need for multidisciplinary coordination. However, multidisciplinary review of interactions between different conditions occurred only once. This was upon specific request from an informant who realized that two condition-specific treatment plans conflicted.

Multidisciplinary coordination within one condition occurred for two informants. The informants took part in monthly (mental health) and bi-annual (parents to the child with multiple disabilities) planning meetings respectively. Even though the former of these two also had diabetes, they never discussed care for diabetes in the mental-health coordination meetings. One informant felt the team meetings were helpful, while the other characterized the team meetings as follows:

“There are care planning meetings every six months. At these meetings, the participants typically “look at the floor” when tasks are distributed. The coordinator is very good, but it is clear that there are limitations to

what she can do. At these meetings, we try to find out what should be done, who does what, and when, right? (...) But, it's almost as if the participants want to crawl underneath the table, and not look at me. It is as P [partner] says, a parody. You're so mad when you leave those meetings because there is no energy, no support. Quite to the contrary." Parents of a child with multiple disabilities.

Care delivery

The system is responsible

All patients emphasized that they find care professionals, in general, to be caring, polite and compassionate. They often described good care as being treated as a person and not a diagnosis.

"But for the most part, I have met, yes, persons you could call angels. (...) They [the oncology nurses] were so humane and warm and good. It was a good experience to come to them and feel their concern for you." Woman, breast cancer.

Despite the hard work and good intentions of the individual professional, slips occur, in which case informants perceived the "system" to be at fault. System shortcomings mentioned by participants were: stress, shortage of time, personnel or both, the traits of the organizational unit, or the system as a whole. Also, informants were "blind" to the organizational barriers and roles of different providers.

"The worst about our care system, in which I include all psychiatric and substance abuse services and the whole package, it is when you are unable to voice your problems. When you are so far down there that you cannot make them listen, you are not seen, not heard. And I feel that it is in such a contradiction to what healthcare is really there to do. You feel inferior, you feel invisible, and you feel so lost. It is as if you're not worth anything." Male, mental health and substance abuse issues.

This focus supported our growing awareness of the entire continuum of care, i.e., "the system" as the agent delivering care instead of individual professionals. The patients reviewed their iPP regarding how the system creates and supports a "common" understanding of what the goal for this person's iPP is, what the care plan is aiming to achieve, and what each contributor's role/task relative to that goal is. It is no longer a question of each professional doing the right thing within his/her professional domain. It is more a question of whether the

professional actions align with the other professionals, the care plan, and the overarching goal.

Delivered according to plan

The expectation of care delivery according to plan was strong with all informants. This was also the issue that most demonstrated the difference between event-based and process-based evaluation of care. The informants based their expectations on what their providers had told them would happen. If the next provider in the chain of care did not comply with the plan, this was cause for a range of reactions, from mild acceptance of the care systems fallibility to strong emotional responses towards a flawed and unreliable system.

"I used nine days to get the prescriptions I should have been given so that I could start treatment [anti hormonal adjunct treatment for breast cancer] in January. And it was a little bit... In the end I had to say: "Who is responsible here?" At that point I had gone to the mammography center, the oncology department, and the oncology outpatient clinic... And in the end, I said to them – I am NOT leaving. Now you MUST find me a doctor who can listen to my challenge which is to get the right prescriptions for the medications that I should have begun taking yesterday." Woman, breast cancer.

Eleven of 19 informants reported failures of delivery of planned care in their iPP. The most common were missing invitations and referrals to planned clinical assessments and examinations, missing prescriptions and miscommunications. One informant, who had been assigned a professional coordinator, described how the implementation of planned activities rarely proceeded as expected unless they "pushed for action."

Informational continuity

All informants could confirm that they had to tell their story over and over. In some cases, relevant information was not available in a timely manner. For example, the hospital discharge summary for one informant arrived a month after discharge, long after both the nursing home and the GP had adjusted medications many times. Informants did not expect to meet the same healthcare professionals every time. Informants acknowledged, rather good-naturedly, that professionals vary regarding their assessments of the clinical diagnosis and care. This causes confusion but is perhaps also inevitable.

"There are as many opinions as there are doctors. The doctors are of course wonderful, but it was truly interesting to come straight from the doctor's consultation to the oncology nurses who said: Don't

listen to the doctors. We are the ones who know!"
Woman, breast cancer.

Evaluation

There was no evidence in the EHR that suggested that patients and/or professionals had evaluated goal attainment in any way. Informants confirmed, that they had not participated in any assessment of goal attainment, or care evaluation in general. Such an evaluation would ideally be directed at the care coordinator/case-manager or to the care team, to support the adjustment of the care plan before the next care cycle.

From ideal to framework – What does our study add?

We incorporated the findings into our evaluation framework of the PC-IC process through the operationalization table. The following ten quality attributes are additions to the PC-IC framework:

- 1) The unit of evaluation is the long-term iPP process, not the care-event, or series of care events.
- 2) The iPP process consists of four stages, each with distinct desired quality features.
- 3) All stages build on each other, starting with the overarching goal based on the person's answer to the question "What matters to you?"
- 4) Identifying "What matters to you?" may not be straightforward. Building trust and being creative in inferring goals from other statements may be necessary. What matters may vary widely from a biomedical problem to a life area.
- 5) Not all life-goals are health-care concerns. Therefore, the overarching goal must be translated, in an open and non-judgmental process, into realistic and relevant goals of care. This type of negotiation requires good communication and balancing skills.
- 6) The range of skills and capabilities that need to be involved in the iPP, flow from the goals relevant for care. These goals lead to the identification and involvement of necessary skills and competencies wherever they can be found.
- 7) The care planning starts with assessing and negotiating the overarching individual goals, and proceeds to build on relevant evidence-based guidelines, not the other way around.
- 8) Care integration is achieved when all the different skills and competencies are effectively orchestrated into supporting the goals of care negotiated between the patient and the healthcare provider.
- 9) 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 expected and planned care.

10) Goal oriented care must include a goal-evaluation.

If providers do not assess success or failure, then no learning or adjustment will occur (Table 2).

Summary of findings

Our contribution is the description of a goal-oriented PC-IC cyclical process framework for evaluation purposes.

An empathic and sensitive exploration of "What matters" is the basis for understanding what the "overarching goal" for the iPP is. From there flows a set of negotiated goals relevant for care, the care plan, care delivery, and care evaluation. We found that the informants assessed their care in terms of their long-term life goals, although some also focused on biomedical goals. Care planning was common for short-term single diseases, but not for long-term multimorbidity. Informants viewed the "care system", not the individual professional, as responsible for care delivery. The application of the PC-IC process framework to patient experiences showed that providers do not record nor share goals, care plans, monitoring of care delivery nor goal evaluation for persons with multimorbidity across the care system.

We were able to demonstrate the fragmented and profession-centric nature of current care delivery. Based on the lessons learned, we characterized each of the four PC-IC stages using: 1) ideal descriptions, 2) key questions and 3) supporting literature references. The resulting framework allowed us to evaluate the PC-IC aspects of 19 multimorbidity iPPs consistently.

Discussion

The iPP quality assessments

As PC-IC is high on the political agenda, the need to support change management towards PC-IC is substantial. The "PC-IC process model" that was proposed and refined in this study was intuitive to informants. With this mental model, persons were able to express what mattered most to them, and assess care delivery relative to their personal goals and care plans (or lack thereof). We identified issues that other studies do not commonly identify as challenges in the literature on PC-IC:

- 1) **The salience of biomedical goals.** Informants were most concerned and upset with immediate unmet medical needs and slips in expected care delivery. It was surprising to us that this was a substantial finding. In most of the person-centered care literature, there is a focus on the patients' needs as individuals [5, 65]. Our findings highlight the importance of ensuring that the person's biomedical concerns are not lost in the exploration of "What matters to you?" [33, 66]. The numerous patient safety complaints in this study seemed both

Table 2 Characterization of the four stages of the Person-Centered Integrated Care (PC-IC) cyclical process for evaluation of individual Patient Pathways (iPP)

Description of ideal care	Key questions	Supporting literature
<p>1. Goals</p> <p>The unit of observation is the long-term iPP. The ideal iPP should meet the overarching personalized goals, which reflect "What matters to the person." The overarching goal defines the scope of the care plan. It includes;</p> <ul style="list-style-type: none"> • an empathic and sensitive effort to understand what the person's needs, values and preferences are • Negotiating and documenting goals of care that are relevant, realistic and observable. • eliciting and recording the person's resources as a partner in decision making regarding health and wellbeing <p>Overarching personal goals can be broken down into supporting sub-goals in a goal hierarchy.</p> <p>In case of conflict between professional recommendations and personal goals, the person's goals should prevail, unless they compromise legal or ethical principles. In case of legal or ethical barriers, a documentation of how the conflict was explored with the person and what conclusions were reached is desirable.</p>	<p>How do persons express "What matters to them?"</p> <p>What are the patients' perceptions of healthcare's reaction to his/her articulation of "What matters to them?"</p> <p>Did the informants express unmet needs, values or preferences?</p> <p>If there were unmet needs, conflicting view of goals, were these described or explained in the EHR?</p> <p>What needs for self-management support do informants voice, and were these needs met?</p>	<ul style="list-style-type: none"> • Goal-oriented care [31, 35, 83] • The informed, active patient [84] • Patient-centered care [33] • Person-Centered care [85] • People centered care [86] • What matters to you? [63, 64] • Self-management support, patient involvement, and engagement [87] • Self-determination theory [88] • The ethics of authenticity [89]
<p>2. The care plan</p> <p>The care plan is based on a multidisciplinary review of the goals from step 1. The first step is to identify skills and competencies needed to achieve these goals. There are no organizational limits regarding whom to include in the iPP plan.</p> <p>The decision process should involve all relevant providers and the patient/caregivers as far as possible to promote engagement, realism, and ownership of the plan.</p> <p>Plans take into account and document the patient's resources as a partner in the collaborative work for health and wellbeing</p> <p>The care plan should ideally;</p> <ul style="list-style-type: none"> • Be committed to and aligned with personal goals • Be evidence-based • Include a multidisciplinary review in cases of multimorbidity • Ignore organizational boundaries • Describe self-management and its support • Describe monitoring for exacerbations • Include a crisis management plan • Include a time and method for goal evaluation. • Include community resources that can be leveraged to help meet goals 	<p>Was a written or verbal care plan described in the EHR, or by the patient?</p> <p>What are the patient's descriptions of involvement and engagement in care planning and shared decision-making (SDM)?</p> <p>What are the EHR descriptions of SDM?</p> <p>Do care plans include the following components:</p> <ul style="list-style-type: none"> • Reference to personalized goals? • Self-management support? • Multidisciplinary review whenever relevant? • Monitoring for exacerbations? • Emergency or crisis management? • Checkpoints for evaluation of goal attainment, or goal revision? 	<ul style="list-style-type: none"> • Shared decision making [90, 91] • Prepared proactive healthcare team [84] • A personalized care plan [50, 92] • Decision support [84] • Evidence-based medicine [91] • Self-management support, patient involvement, and engagement [87]
<p>3. Care delivery</p> <p>Care delivery builds on the care plan from step 2. The delivery of care is a system property, not a feature of individual professionals. The care system should identify the resources necessary to reach overarching goals irrespective of organizational boundaries and responsibilities.</p>	<ul style="list-style-type: none"> • Was the care plan operationalized to show where, when and who would provide their care? • If so: What was the perceived usefulness of such operationalized plans? • Did patients experience unexpected care events? 	<ul style="list-style-type: none"> • Delivery system design [84] • Community resources [84] • Care pathways [94] • Continuity of care [93]

Table 2 Characterization of the four stages of the Person-Centered Integrated Care (PC-IC) cyclical process for evaluation of individual Patient Pathways (iPP) (Continued)

Description of ideal care	Key questions	Supporting literature
A marker of high quality care delivery is that the person feels that he/she is seen, heard and recognized as a person. Seamless care delivery depends on the recruitment of the resources that will implement the care plan with attention to Continuity of Care, and it's organizational, informational and relational dimensions as described by Haggerty [93]. Haggerty's "relational continuity," serves primarily to elicit and communicate "what matters" to the system. Thus, we argue that "relational continuity" is a kind of informational continuity.	<ul style="list-style-type: none"> • Did patients have to intervene to correct mistakes because expected care delivery was not provided? • Were patients directed to community resources outside of the healthcare system such as peer support organizations or social services? • What were patient's statements regarding the organizational, informational and relational continuity of care across their iPP? 	
4. Goal attainment		
The iPP success is measured by the degree of goal attainment of goals set in step 1. Goal evaluation enables learning and adjustment of the iPP for the next turn of the care cycle.	<ul style="list-style-type: none"> • Did they plan and assess goal attainment? • If so: Did they adjust the future care plan according to lessons learned? 	<ul style="list-style-type: none"> • Health and Functional outcomes [84] • Goal oriented care [31, 35, 83, 75]

Descriptions of ideal care, key questions, and literature underpinnings to support a consistent evaluation of care across observers and informants

legitimate and important. With the internet revolution, patients are both more informed and connected to relevant resources that can support their evaluation of biomedical issues [67]. Other studies also suggest that persons with multimorbidity experience more quality challenges than persons with only a single condition [3, 68, 69]. Cook [6] claims that all healthcare is by nature fragmented and that bridges are constantly "invented" to ensure that the right thing happens at the right place and time. He claims that gaps occur when "...conditions overwhelm or nullify the mechanisms practitioners normally use to detect and bridge gaps" [6]. It may be that the complex needs of our informants routinely "overwhelm" normal care practices. Although patients cannot be expected to assess all aspects of technical quality, it is likely that the introduction of a regular goal-oriented PC-IC process evaluation, could detect obvious slips in the technical quality of care.

- 2) **The overarching goal defines patient-experienced quality.** Another significant finding is the lack of attention to the ensemble of the person's needs and challenges and the failure to share overarching goals and care plans with all relevant parties. We found the ideal PC-IC plan to be defined by 1) the person's long-term goal and 2) to include a system-wide perspective, "blind" to organizational arrangements between providers. While it is encouraging to note that mental health and rehabilitation services comply more often with

PC-IC ideals, even these services often limited their scope of the care plan to one main condition. Our findings are in line with other reports which describe care systems as focused on professional and diagnostic centric goals [4, 48, 70–72]. Health professionals focus on disease control, while patients link goals to meaning and well-being (e.g., employment, family) [22, 65, 72, 73].

- 3) **Goal-oriented process, not event evaluation.** Our findings differ from those derived from tools and frameworks for PC-IC that typically focus on care event(s), or events by a given provider [1, 40–45]. The essence of person-centeredness is to allow the answer to the question: "What matters to you?" to define the quality of the whole care process. We acknowledge that a need for a more focused and time-limited evaluation can be legitimate. A review of limited events, with their concomitant sub goals and sub-plans can accommodate this. Yet, we would argue that it is essential that event sub-goals remain properly aligned with the overarching goals of the person and are ranked within the entire set of sub-goals and activities going on.
- 4) **The translation** of the overarching goal into relevant and realistic goals of care is a complex negotiation and balancing act. In this material, the negotiation process regarding the legitimacy of biomedical goals was frustrating for the informants. There were also examples of conflicts between the explicit person and professional goals. The most

glaring finding is, however, the missing negotiations, indicating that the actionable goals are taken to be self-evident and not in need of negotiation.

Our results indicate that the PC-IC process framework for the evaluation of care has the capability of capturing; 1) the quality of a goal identification process, and 2) the system's (in)ability to share goals, care plans, delivery monitoring and goal evaluation across relevant contributors. The PC-IC process framework can thus provide a basis for the development of new qualitative and quantitative tools, which can support management of change in the direction of PC-IC ideals.

Development of PC-IC evaluation tools

Measurement is one key to system change: It gives the basis for assessment of where we are at, and can represent a guide to adjustment and improvement efforts [74]. The process of capturing patient stories, as we did, is too cumbersome to be pragmatic in large-scale health service evaluations. However, the informants' intuitive grasp of the framework is encouraging and attests to the feasibility of pursuing this line of inquiry.

This methodology may form the basis for the development of evaluation tools built on both qualitative and quantitative methods. To be useful, the process needs to be simplified, both regarding administration and analysis. We see two apparent routes of further development: 1) Interview guides for personnel who are familiar with the person's history, based on the key questions. 2) Structured questionnaires that gather qualitative or quantitative responses that rely on the person's recollection of his/her history. Such surveys can, with enough explanation, be filled directly by the person with the support of health personnel if necessary. Qualitative statements may provide useful feedback directly to care providers. For aggregate data at the population level, data must be quantifiable. Quantitative measurement instruments of person-specific goals [75–77] can be merged with our four-stage PC-IC care process to create such tools.

Implications for practice and the EHR

By endorsing the PC-IC process ideal as an evaluation tool, we are also making a normative statement about care for patients with multimorbidity. A growing knowledge base supports the importance of PC-IC coupled with a goal-oriented process [14–21]. However, even though the field is learning rapidly, the literature in this area is still widely heterogeneous and inconclusive concerning which care components are necessary and sufficient, for whom and in what contexts [19, 78, 79]. Our recommendations therefore still need further validation regarding implementation and effect on iPP experiences, health outcomes, and cost-benefit results.

An essential tool to support cohesiveness across the care system is the EHR. In our Norwegian context, EHRs are available in all GP, nursing services, and secondary care settings. However, the EHRs mirror strict organizational, legal and economic silo patterns. Except for limited two-way electronic messages and communication such as the exchange of discharge/referral letters, there is no standard electronic interface which supports the interactive and updated sharing of goals, care plans, care delivery monitoring or goal evaluations across organizations. It seems logical, although data are still sparse on this issue, that such electronic tools would be helpful [80, 81].

Strengths and limitations

The combination of EHR derived summaries and interviews was an effective way of gaining insights into complex care stories. Even with a considerable variation in individual conditions, we experienced a sense of saturation for all four areas of assessment. The findings resonate with both theory and other empirical studies in the field, lending credibility, and relevance to the study.

This study examines one domain of quality of care. Quality is a multi-dimensional construct, and there are many other quality domains not evaluated here [82]. Notably, patients cannot be expected to assess the area of technical quality. Our method of evaluating quality should not exclude the review and assessment of other quality domains in the iPP.

Due to resource limitations, we made iPP timelines and summaries based on the GP, hospital, and nursing service health records only. Ideally, we should have included all health services and all service providers, as well as informal caregivers. It would also have strengthened the study if we could have interviewed the child with a disability in addition to his parents.

This study raises concerns regarding the quality of care for persons with multimorbidity, but the small sample size does not allow for generalizations. There is also a need for validation of our framework in other settings and conditions. Persons with only a single condition or less complex care needs may not recognize these concerns as readily.

Conclusions

This paper provides insights and methodology that may support quality evaluation towards a goal and process-oriented PC-IC ideal of chronic care. Use of this evaluation method revealed important weaknesses, commonly associated with fragmented and discontinuous care for multimorbid informants. This paper highlights how gaps in care that are invisible with an event-focus on quality of care, becomes visible when we use a long-term goal-oriented PC-IC process as an ideal.

Endnotes

- ¹Connect study only
²TO study

Additional file

Additional file 1: Interview guide. (DOCX 15 kb)

Abbreviations

EHR: Electronic Health Record; GP: General Practitioner; iPP: Individual Patient Pathway; Multimorbidity: Multiple long-term conditions and/or complex healthcare needs; PC-IC: Person-Centered Integrated Care; TO: Troms-Otøen (a region in Northern Norway)

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Availability of data and materials

Norwegian privacy legislation and the participant "informed consent form", limits data access to the authors GB, DG and AH. Data cannot be shared due to this restriction.

Authors' contributions

All authors contributed to the formulation of the conceptual ideas that were subsequently shaped into research questions. The first author, who has a background as a physician and health service researcher and is the guarantor of the study, read and summarized all EHR-timelines, participated in all but three interviews and did both preliminary and final analyses in dialogue with co-authors. GB, AH, and DG conducted the interviews and wrote interview synopses. GB and DG formulated the PC-IC staged framework. CR, IL, and MR were essential facilitators for informant recruitment and data collection. All authors contributed with critical feedback to drafts, and read and approved the final manuscript. The authors represent a multi-professional background (medicine, psychology, occupational therapy, general practice, nephrology, health service decision maker, and nursing) and some also had considerable patient experience.

Ethics approval and consent to participate

Both the Connect (application # 2010/3396/REK sør-øst B) and TO-study (application # 2011/1913) were submitted to the Regional Ethics Committee (REC) for assessment. REC approved the former, while REC waived the need for approval for the TO-study. The Regional Data Protection Officer approved both studies. Informants were contacted by their regular health provider, such as the cancer nurse, their primary care nursing contact, their GP, or by a representative of their local patient organization on behalf of the study. Eligible patients were informed about the aim of the study and provided with written information and the informed consent form. The participant contact information was forwarded to the research team only when the informed consent form had been signed. For the under-age child, the child's parents consented to participate in the study on the child's behalf.

Competing interests

The authors declare that they have no competing interests.

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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 avgrensning 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

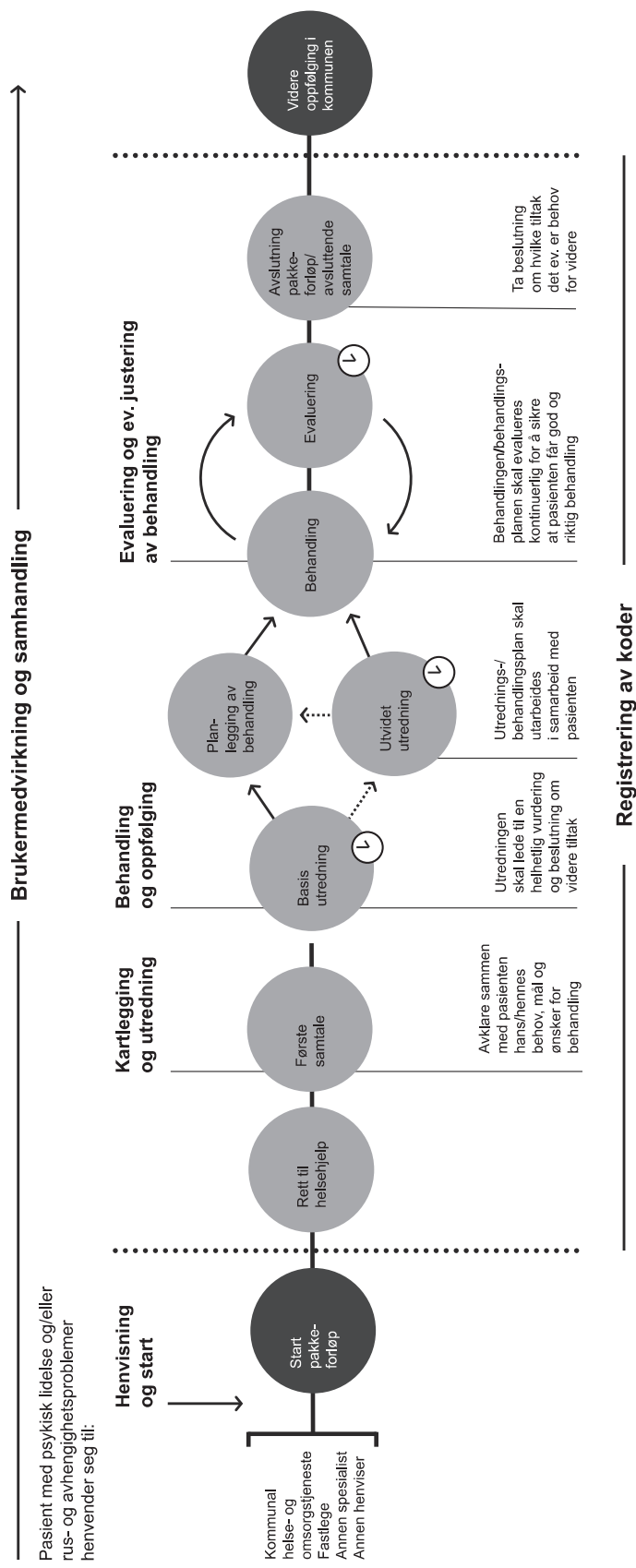
Flowchart

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



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 Bønaa, 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
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