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ICT in ICP: Analysing user participation in testing of a web-based tool for Individual Care Plans

Thesis for the degree of Philosophiae Doctor

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Norwegian University of Science and Technology
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List of papers

Paper 1: Jorunn Bjerkan, Marie Richter, Anders Grimsmo, Ragnhild Hellesø and Jytte Brender: "Integrated care in Norway: the state of affairs years after regulation by law." *International Journal of Integrated Care.* 2011, 11: 1-8.

Paper 2: Jorunn Bjerkan, Marianne Hedlund and Ragnhild Hellesø: "Patients' contribution to the development of a web-based plan for integrated care-a participatory design study." *Informatics for Health and Social Care 2014* (0): 1-18.

Paper 3: Jorunn Bjerkan, Solfrid Vatne and Anne Hollingen: “Web-based collaboration in individual care planning challenges the user and the provider roles – toward a power transition in caring relationships.” *Journal of Multidisciplinary Healthcare* 2014 (**7**): 561-57

Acronyms and abbreviations

AR	Action Research
CNRHA	Central Norwegian Region Health Authority – the hospital trust of mid-Norway
EPR	Electronic Patient Record
GP	General Practitioner
HiNT	Høgskolen i Nord-Trøndelag (Nord-Trøndelag University College)
ICP	Individual Care Plan
ICT	Information and Communication Technology
NSEP	Norsk Senter for Elektronisk Pasientjournal (Norwegian Research Centre for Electronic Patient Records)
PAR	Participatory Action Research
PD	Participatory Design
PKI	Public Key Infrastructure
PR	Participatory Research

Sammendrag (norsk)

IP med IT:
En studie av brukermedvirkning i utprøving og bruk av et internettbasert system for individuell plan.

Individuell plan (IP) er en norsk strategi for samhandling i helse –og sosialsektoren for pasienter eller brukere med behov for langvarige, koordinerte tjenester.

IP-strategien har som formal å øke og forbedre tverrfaglig og tverrsektoriell samhandling, og legger vekt på pasientmedvirkning i planprosessen. Individuell plan viste seg å være krevende å få implementert, og nettbaserte verktøy ble etterspurt.

Hovedmålet med denne avhandlingen var å undersøke på hvilken måte et internettbasert verktøy for individuell plan kunne bidra til målene som var satt i de nasjonale føringene.

Gjennom to delstudier så vi på hvordan individuell plan var tatt i bruk i kommunene, og hvordan en internettbasert IP fungerte for involverte i planarbeidet.

I den første studien, en spørreundersøkelse med svar fra 62 kommuner, fant vi at én av 200 innbyggere (0, 5 %) hadde en individuell plan, mens de nasjonale estimatene var at én av 33 (3 %) hadde behov for IP. Vi fant ingen signifikante forskjeller mellom antall individuelle planer eller hvordan IP-arbeidet var organisert sett i relasjon til partipolitisk styring i den enkelte kommune. Sosiale forhold blant innbyggere i en kommune eller kommunens økonomi utgjorde heller ingen forskjeller når det gjaldt antall opprettede planer. Kommunalt ansatte sykepleiere, lærere og sosionomer utførte storparten av IP-arbeidet. Sykehusansatte og fastleger deltok i mindre grad. Fysiske møter var den foretrukne samhandlingsformen.

Kommunene hadde etter fem år ikke klart å få individuell plan til å fungere som forutsatt.

I studie II, hovedstudien, fulgte vi et utprøvingsprosjekt, «SamPro-prosjektet», i Midt-Norge. I denne studien deltok 54 voksne pasienter og foreldre til 22 barn med IP sammen med 158 tjenesteytere i utprøving, og videreutvikling av et nettbasert system for IP. Vi fant at pasienter og foreldre bidro til forbedring av systemfunksjonaliteten og brukeropplevelsen gjennom å teste systemet med sin egen IP. Pasienter/foreldre var i starten opptatt av å ha tilgang til systemet og få opplæring i bruk av det. Dernest var de opptatt av hvordan løsningen kunne gi tilgang til planens informasjon som de hadde behov for i hverdagen. Til sist konsentrerte de seg om hvordan systemet kunne forbedre samhandlingen mellom partene.

Et annet hovedresultat var at nettbasert IP (e-IP) utfordret rollebildet. Både pasienter/foreldre og tjenesteytere utviklet en proaktiv eller passiv rolle i sitt samarbeid når de brukte det nettbaserte systemet. Vi fant det tradisjonelle forholdet med en aktiv tjenesteyter som tok ansvar for planarbeidet på vegne av en mer passiv pasient. Aktive parter ga god planaktivitet. Der begge parter inntok en passiv rolle stoppet planarbeidet opp. Vi fant en ny konstellasjon, IP-samarbeid mellom proaktive pasienter/foreldre og passive tjenesteytere: Her kunne planarbeidet likevel fungere fordi pasientene/foreldrene selv hadde tilgang til planverktøyet og den lagrede informasjonen i planen sin via internett. Noen av pasientene så en mulighet til å ta mer ansvar for eget planarbeid. Dette var en ny forståelse av deres pasientrolle sett i forhold til en mer tradisjonell pasient/tjenesteyter-konstellasjon.

E-IP utfordret IP som konsept: Pasienter og foreldre til barn med IP kunne få bedre kontroll, og innta en myndiggjort eller «empowered» rolle ved å ha tilgang til, og bruke denne nettbaserte løsningen. Vi observerte en maktforflytning fra tjenesteytere til tjenestemottakerne i planprosessen. På den annen side: ulike forutsetninger for å kunne ta i bruk slike nettbaserte løsninger begrenset også den digitale samhandlingen rundt individuell plan for enkelte av pasientene og foreldrene, noe som er en viktig faktor å ta hensyn til i videre utvikling av digital samhandling mellom helse- og sosialsektoren og aktuelle tjenestemottakere.

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Summary (English)

ICT in ICP:

Analysing user participation in testing of a web-based tool for Individual Care Plans

Background

Individual care plan (ICP) is a Norwegian solution for integrated care in health care and social care for patients in long-term need of coordination of health- and social care services. The ICP strategy aimed to increase and improve multi-professional and cross-organizational collaboration to improve quality and efficacy in care. ICP invites patients as partners in planning. The ICP proved to be challenging to implement due to various obstacles, and a web-based tool for planning was demanded.

Objectives

The main purpose of this PhD project was to explore in what way a web-based solution for an individual care plan could contribute to achieving the goals in the governmental ICP-strategies:

- What characterizes and describes the results of the implementation and use of ICP in Norway a few years after new legislation was introduced by law and regulations?
- How can patients contribute to the development of ICT systems for ICP?
- How does web-based collaboration between care professionals and patients influence the caring relationship?

Methods and materials

In study I, we randomly chose 92 municipalities for a questionnaire survey. We analysed data from 61 respondents. In study II, the main part of this research project, we followed the SamPro testing project in mid-Norway in an action research design. 54 adult patients, and parents of 22 child patients as well as 158 care professionals participated in system use, development and -testing. Data included field studies and interviews.

Results

In study I, we found that one in 200 citizens (0. 5 %) had an individual care plan, while governmental estimates were about one in 33 (3 %). Local political government was not associated with significant differences in the numbers of plans or the way that ICP was organized. Neither did the social or financial situation in the municipality make a difference in the use of plans. Municipal nurses, teachers and social care professionals performed most of the ICP work. Hospital staff and general practitioners contributed less. Patients having a plan contributed in planning. Face–to-face meetings were preferred for plan collaboration.

The first main findings in study II were that patients' contribution to system testing improved the SamPro system and its functionality and usability. Patients were concerned about (1): system access and system training: "*towards accessing a web-based tool for ICP",* (2): how SamPro could *"become a tool for information"* in their everyday life, and finally, (3): how this tool could "*become a tool for interaction"* to meet their needs for contact and collaboration with care professionals. Another result in study II showed that use of e-ICP challenged the roles of those involved. Both patients and care professionals developed a proactive or reluctant role in their e-ICP collaboration. We saw a new constellation: proactive patients with reluctant care professionals could make planning work because the patients themselves had access to the system and information stored in it. Proactivity or reluctance became visible on both sides and some patients saw an opportunity to take more responsibility for their care planning. This was a new understanding of their patient role in relation to the traditional patient/provider constellation. A power transition took place from care professionals to patients in the care process leading to patient empowerment.

Conclusions

Action research and participatory design proved to be sustainable methods to study user participation in an unpredictable testing situation.

E-ICP challenged the concept of integrated care: patients and parents of child patients could gain control of life and attain an empowered role through the access and use of the e-ICP solution, but the digital divide among testing participants also restricted collaboration in e-ICP testing.

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1 Introduction

This dissertation focuses on a Norwegian solution for integrated care: individual care plans (ICPs) and pilot testing of a web-based device for ICPs in mid-Norway. In study I in the thesis, I explored the implementation and use of ICPs in Norwegian municipalities a few years after ICP was introduced. Study II, the main study of the thesis, showed how patients could contribute to system development of a web-based tool. It also showed how shared access to and use of the e-ICP planning tool challenge the roles of care professionals and patients. This research is motivated by the need to find high-quality efficient and suitable solutions for coordination of care including patients as partners in planning for their own health conditions.

For various reasons, patients' situation has changed during the past generation. This is described more in detail in chapter 3.2. To take on the role of a patient has been and may still be hard work. It may be even harder to take on the role of a person living with a chronic disease. Being born with or acquiring a disability is another challenging situation for some people, which may restrict fulfilment of their potential in life compared with fellow citizens (Ramm and Otnes, 2013). Both disabled persons and chronically ill patients become more or less dependent on help and care from others, based not on their own wishes, but on pure necessity (Baert et al., 1992, Gignac et al., 2000, Ellefsen, 2002, Moe et al., 2013b). Psychiatry, tuberculosis and disability are examples of areas that reflect stories of prejudice, shame, incapability and lives in large centralized institutions with limited contact between patients and the rest of society (Schiøtz and Skaset, 2003, Gleeson, 2010).

During the past generation, people living with these conditions in western countries have managed to work their way out of their often stigmatized and isolated life situation. From the middle of the twentieth century, the same groups were increasingly regarded as equal participants in their community (Cahill, 1998, Anspach, 1979, Chamberlain, 1990). Life conditions were slowly improving due to medical developments that led to improved treatment and care (Skolebekken and Lian, 2003). This trend of improvement in care was also driven forward by citizen movements and political initiatives (Anspach, 1979, Crimmins, 2004). Aware of these improvements, patients of today expect better care and follow-up in their life situation than they did a few decades ago (Kildal and Elvbakken, 2006, Heløe, 2010). Even if life circumstances and health care services have changed during recent generations, patients' hope or hopelessness, fear or anger, and their own strength to fight their way through life with illness or disability may still remain a challenge (Moe et al., 2013a). Only a generation ago, patients with problems related to illness or disability had fewer professionals to consult – perhaps only the family doctor and the local nurse. Today, people have greater access to health care information from a variety of information sources even besides the increased number of professionals (Tjora, 2008, Halvorsen, 2005, 3.ed.). This in turn increases expectations about health care services (Kildal and Elvbakken, 2006, Heløe, 2010).

Being a care professional who meets and cares for patients with chronic illness or disability is regarded as demanding and complex (Martin and Sturmberg, 2009, Moth et al., 2012). Care professionals will often be involved for longer periods, and they are expected to provide long-lasting professional treatment and care to improve life circumstances for these patients (Taylor et al., 2008, Corcoran et al., 2013). Higher expectations and demands from patients and in the population in general call for a variety of skills and knowledge to meet these requests and demands (Wens et al., 2005, Wiebe et al., 2014). Each care profession continuously develops its specialties in response to the wishes and expectations of patients and the public. Escalating specialization may work against a collaborating care service. It may be a challenge if specialization creates organizational or cultural thresholds to overcome in caring chains (Coleman, 2003, Horvitz-Lennon et al., 2006, Gastelaars, 2009). Only a few publications from the last three years seem to focus on fragmentation in health care services or challenges to collaboration as their main research topic (Skolarus et al., 2012, Price et al., 2013, Knai et al., 2014). Articles most often present fragmentation as a fact, aiming to study or review various collaborative solutions to solve fragmentation challenges (Moore et al., 2012, Joo and Huber, 2014, Whiteford et al., 2014).

In parallel with the need for specialization, there is a growing need for professional teamwork to share this specialized knowledge in clinical everyday life. Clinicians often need trans-organizational and cross-professional collaboration to solve a single patient's problem (Chen, 2009, Poulymenopoulou et al., 2013). Editorials and original research from relevant journals and conference papers for the last three years show that the theoretical framework for conceptualization of collaboration in care continues to be important (Van Houdt et al., 2013, Evans, 2014, Burt et al., 2014). Several studies focus on collaboration in care from a political or an organizational perspective, including methods for various measurements (Harris et al., 2013, Tsasis et al., 2013). Other studies have a clinical scope, often accomplished in care of elderly people based on professionals as informants (Bordonaro et al., 2012, Looman et al., 2014), while studies that include direct patient participation in collaboration still seem to be an upcoming perspective in research (Davoody et al., 2014, Mastellos et al., 2014).

Both in Norway and internationally, politicians have given signals for increased digital communication and collaboration in health care services (WHO, 2005, S@mspill 2007, 2004, Johnson et al., 2013), and new technological solutions are being developed and tested (Macyszyn et al., 2013, Pimintel et al., 2013). Scientific publications for the last five years reflect that health care services have implemented multidisciplinary digital communication and collaboration in various ways (Skilton et al., 2010, Jensen, 2013, Wells et al., 2013).

At the same time we see a significant number of studies reporting on online communication between care professionals and patients or patient`s online access to their own health care information (Kane et al., 2013, Gonzales et al., 2014). Yet another approach is public access to and use of health information or lay group networks on the internet (Mayer et al., 2011, Attard and Coulson, 2012, Fokkenrood et al., 2012, Kim, 2015). The use of digital devices and internet communication enables collaboration in health care services. There are nevertheless still challenges, both in developing tools appropriate for care professionals, or in reaching certain groups in the public through the internet (Petersen et al., 2013, Tully et al., 2013, Kontos et al., 2014, Damodaran et al., 2014, Dent and Tutt, 2014).

2 Aim of the study

The main purpose of this PhD project was to explore in what way a web-based solution for an individual care plan could contribute to achieving the goals in the Norwegian government's ICP strategies.

For this purpose, this PhD project focused on these research questions and activities:

- What characterizes and describes the results of the implementation and use of ICP in Norway a few years after new legislation was introduced?
- How can patients contribute to the development of ICT systems for ICP?

How does web-based collaboration between care professionals and patients influence the caring relationship?

3 Theory and policy

3.1 Integrated care, a theoretical approach

Collaboration in caring services has been developed over the years from informal models of collaborative care practice to a more formal theoretical approach. “Integrated care” is present in health care services in somewhat different forms and described in different terms due to the national or even local health care systems in each country (Leichsenring, 2004, Valentijn et al., 2013). Other names are used for familiar models of collaborative care: “shared care” is one synonym: another is “continuity of care” (Fleury, 2006, Uijen et al., 2012). With some variations, they all describe the aim for cooperation or collaboration between care actors in a narrow or broader field of care, only occasionally including patients as partners (Hellesø and Lorensen, 2005).

There are various definitions or descriptions of integrated care, and it is not always obvious whether these definitions aim to clarify integrated care as a practice or a model or to define it as a theory. Leutz (1999) presented a definition for integrated care as a theoretical approach:

> “The search to connect the healthcare system (acute, primary medical and skilled) with other human service systems (e.g., long-term care, education and vocational and housing services) to improve outcomes (clinical, satisfaction and efficiency).” (Leutz, 1999).

This definition also includes additional human service systems besides medical services at various levels in health care. Ahgren (2012) uses this definition of integrated care in his research:

> “an approach that seeks to improve the quality of care for individual patients and service users by ensuring that services are well co-ordinated around their needs” (Lloyd and Wait, 2005).

Common to these definitions is that they describe the organization of care as a multi-dimensional collaborative activity between various care professionals. Dimensions of care include quality, efficacy and coordination, reflecting organizational and economic approaches together with a clinical-professional approach (Ouwens et al., 2005, Fleury, 2006, Goodwin, 2013).

I will now present various theoretical approaches towards integrated care. Various studies that I have found show that integrated care has been theoretically framed in dimensions of care provided, from general organizational models as precursors later adapted for integrated care (Konrad, 1996) to recent research showing both broad and complex approaches (Janse et al., 2012, Minkman, 2012). The theory of integrated care seems not yet to be a fully formalized model of practice, nor established as one dominant direction. It is more like multi-facetted approaches as shown below.

An early theoretical approach to integrated care was E. Konrad, (1996) presenting a framework for service integration as an integrated care precursor. She described a detailed decrease/increase in service integration at five levels as presented in Figure 1. In her interpretation, the line goes from an informal level (1) information sharing and communication, which include informal relations where professionals shared general client information in staff meetings, or e.g. exchanged general organizational information, not including structured communication between care professionals. The optimal level of integrated care in the theory of Konrad (1996), is (5), the level of integration, a comprehensive level with one single authority. Activities in such an organization are both transparent and fully integrated, e.g. being accomplished at the same location, having the need of each individual client in focus.

In the same period Leutz (1999), described a three-level line of integration in care. In his theory (1) linkage is the starting point for integrating care including situation-based contact and information sharing between professionals. Then (2) coordination in networks is the next level, where there is more structured communication than at the linkage level, still operating within each professional’s core organizational structure. Finally Leutz (1999) introduces (3) full integration, the most integrated level meaning a new organizational structure, a consortium for integrated care being established. This can be established as programmes or new units including integrated care teams operating on a common clinical and/or organizational platform.

In more recent research Ahgren (2012), named the three levels in his theoretical model: (1) antagonism, (2) commensalism, and (3) mutualism, starting beyond the level of integration as “antagonism” describes a separated stage of linkage position. Ahgren (2012) included and broadened Leutz’s levels of linkage and coordination within his second level: the level of commensalism. At this mid-level, one professional partner in the collaborative situation may benefit from the common effort, while the other partner neither benefits nor incurs substantial cost from this collaborative effort. At the optimal position of integrated care, Ahgren (2012) placed the level of mutualism as an opposite to antagonism. In this relationship, both parties involved benefit from the collaborative care accomplished.

Another way of understanding integrated care is to focus on phases of implementing integrated care instead of divisions. This was done in the research of Minkman et al. (2009). (1): The “initiative and design phase” is the starting point for the collaboration between a certain group of care professionals working with identified patients or target groups to work. In phase (2), “the experimental and execution phase”, the work within the group starts. Information is exchanged in the group and procedures are agreed upon. Phase (3) was named “the expansion and monitoring phase”, which includes further development and improvements in a more formalized structure. In phase (4), “consolidation and transformation” is the phase where the integrated programme is the regular way of working for the group members involved. Both financial and organizational structures fit this phase of integration (ibid).

Lining up the described theories, the levels or phases of integrated care could be represented this way:

Upper level of integration:	• Mutualism (4) • Integration(1) or full integration (2) • Consolidation and transformation (1) (3)
Middle level of integration:	• Expansion and monitoring (3) • Collaboration (1) • Experimental and execution (3) • Cooperation and coordination (1) (2) • Commensialism (4)
Lower level of integration:	• Linkage (2) • Initiative and design (3) • Information sharing and communication (1)
No integration	• Antagonism (4)

(1): Konrad, (1996), (2): Leutz, (1999), (3): Minkman, (2009), (4): Ahgren, (2012)

Figure 1. Representation of integrated care levels

In addition to placing various forms of integrated care into levels or phases of care, recent research has categorized integrated care on lines from the public perspective to individual perspectives as shown in figure 2. It has placed the levels of care into dimensions of horizontal or vertical integration – from the same organizational level of care to integrating different organizational levels of care (Valentijn et al., 2013). In the same article, Valentijn described integrated care as hierarchical dimensions from macro to micro levels: at the macro level, we find system integration in the meaning of levels of rules and politics. The following level is organizational integration at the meso level, where inter-organizational integrated care finds its place. The next step, still at the meso level, is professional integration – the extent to which professional care providers coordinate services across their disciplines. Finally, Valentijn (2013) places clinical integration, referring to levels of care service integration, at the micro level. Combinations of integration level approaches should lead to functional integration as “a flexible approach in order to enable partnerships to adapt to the constantly changing environment”. This aims to support and link the levels of integrated care from the micro level (clinicians) to the meso level (the organization they work within) together with the system (politics and rules) at macro level (Valentijn et al., 2013). The macro, meso and micro level could also be linked at a normative level according to Valentijn (2013), defining this dimension as:

> "The development and maintenance of a common frame of reference (i.e., shared mission, vision values and culture) between organizations, professional groups and individuals."

In the normative perspective, the informal coordination mechanisms towards the success or failure of integration of care find their place (ibid).

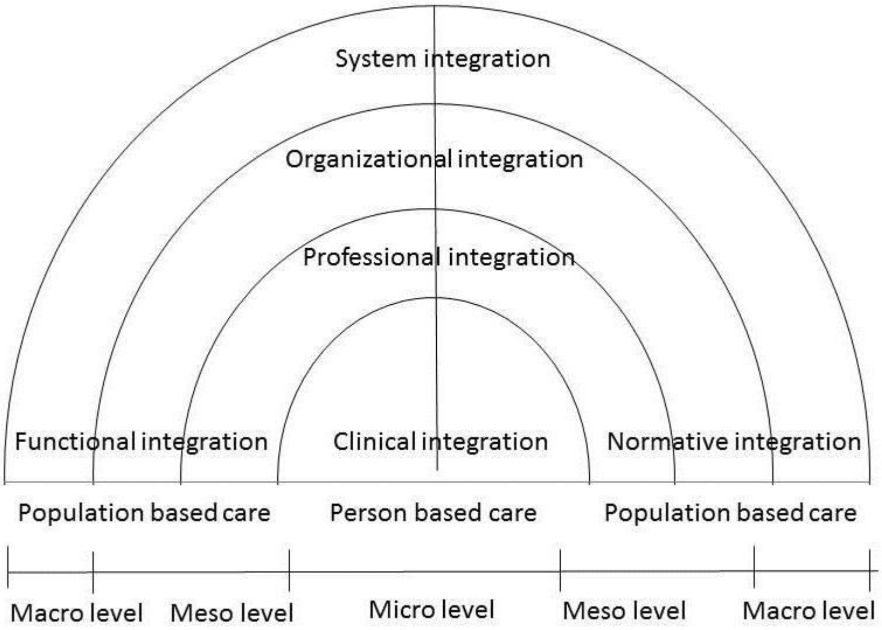

Figure 2. "Conceptual framework for integrated care based on the integrative functions of primary care" adapted from Valjentin et al. (2013)

Relating figure 1 to figure 2 shows the complexity of the concept of integrated care. Both organizational structures at various levels, being normative or functional in the sphere of person-based care or population-based care (figure 2), could each or all also be categorized in the range of antagonism towards full integration (figure 1).

Another recent model for integrated care was put forward by Minkman (2012). His recent model expanded further his former theory of integrated care by including dimensions like “quality of care”, “organization of care”, “effective collaboration” and “results”. Aspects relevant to integrated care were placed within these four dimensions: e.g. the four phases from Minkman (2009) were now extended in Minkman (2012), which is visualized in figure 3.

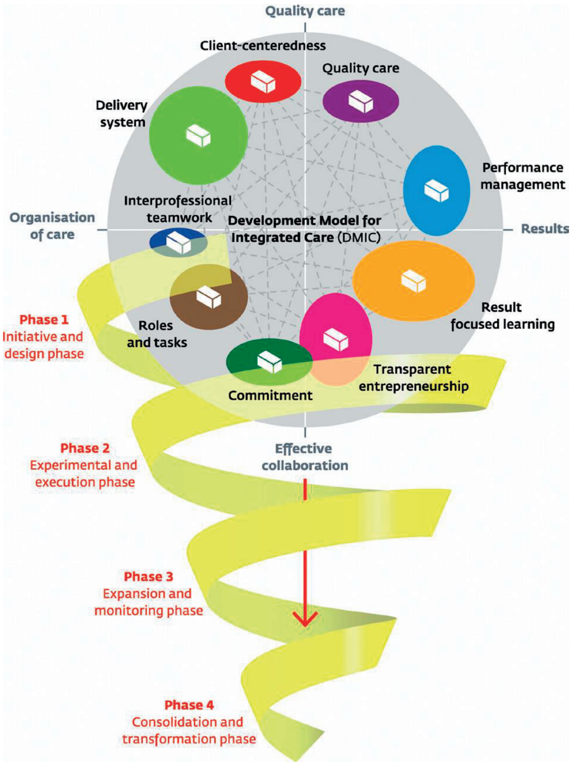

Figure 3: Minkman (2012): “A development model for integrated care”.

In this chapter, I have described integrated care as a model, a practice and an evolving theory. Konrad (1996) emphasized in her study that the definition of integrated services should be broad and inclusive, and not strictly limited to caring services. Although she was one of the early starters, she is still one of few in this research area to include service recipients as named stakeholders in the theoretical conceptualizing of integrated care. Other recent research, like the theory of Valjentin (2013), describes “person focused care” while Minkman (2012) includes “client-centeredness” in his integrated care theory. None of them describe in further detail the role of these service recipients, clients or patients except as being the recipients of integrated care provided by professionals.

3.2 From a passive to an empowered patients’ role in caring relations

The general democratization and liberty movements in recent decades influenced a demand for, and development of democratization and later on individualization of health care service solutions in western countries (Schiøtz and Skaset, 2003, Rose, 2013). People who were influenced by policy movements for citizen rights and freedom of the individual shaped new directions towards health care policy (Freire, 1970, Askheim and Starrin, 2007). “Patient empowerment”, (PE) was developed from such citizen rights movements in the USA, and shaped in various directions due to political ideas and movements in following years (Freire, 1970, Solomon, 1976, Askheim, 2012).

Integrated care strategies were one of many answers to the demand for individualization and personal involvement from citizens and patients based on the long-term growth of Patient Empowerment (Askheim and Starrin, 2007, Spence Laschinger et al., 2010, Colombo et al., 2012). Public-Patient-Involvement (PPI) came out as a more recent answer to these political changes (Andersson and Wilson, 2006). Both PE and PPI as models for caring relations emphasize and demand a patient- and user-centred approach in caring. They include the patient as an equal or even determinant party to the care being offered. Citizens incorporating these strategies are not likely to assume a traditional passivized patient role when they are ill or disabled. They no longer regard care professionals as indisputable authorities (Freire, 1970, Hansen, 2007). Knowledge about health conditions and opportunities for communication through forums such as groups of patients are now available to the public through the Internet. This has strengthened the potential for patients’ influence (Tjora et al., 2010), and the need for professional collaboration in order to respond to patients’ requests (Schiøtz and Skaset, 2003). The increased influence of patient empowerment can be seen through the growing number of scientific publications involving the concept: from less than one hundred publications containing “patient empowerment” in relevant international databases before the 1970s to more than 11000 publications in the same databases in the period of 2001 to 2006 (Askheim and Starrin, 2007).

Many definitions of patient empowerment have been developed, but they all seem to include personal control and self-efficacy or self-mastery, and patients' capacity to make decisions or take control of their own health condition (McAllister et al., 2012, Askheim, 2012). Whether patient empowerment should be regarded as a process, an outcome or both has been discussed (Aujoulat et al., 2008, Holmström and Röing, 2010, Anderson and Funnell, 2010). According to Askheim (2012), empowerment is a complex concept indicating a process:

strength → gathering forces → mobilized power

Askheim (2012), proposes four positions within patient empowerment as shown in table 1:

Table 1. Empowerment positions

A political and collective position :	1: The counter-power position
Individual positions:	2: The market-oriented position 3: The personal self-realization position 4: The therapeutic position

In the collective position of establishment of a counter-power, PE emphasizes that patients become empowered based on their given position in their social or structural environment. The surroundings determine the possibilities for each individual's empowerment through an awakening process. Through awakening and awareness, patients should gain control over their own life conditions as individuals or a group. In this PE dimension, the strengthening of each individual or group is central. Examples of such counter-power position empowerment are establishment of patient groups or individual patients standing up against what they regard as suppression in health care. Examples of counter-power projects include selling street magazines as an occupation for people addicted to drugs and the establishment of user-directed personal assistance for disabled people, enabling them to decide whom they wish to have as a helper and what the helper is to do (Askheim, 2012). The second position, the market-oriented PE, emphasizes each individual as the subject for health care services. In this empowerment thinking, health care should be organized for the support of the patient’s autonomy and independency. The market and free choices for care are offered to patients, replacing a governmental collective welfare system. New public management (NPM) is a main direction for such a market-oriented approach. It has been a dominant policy tool from governments all over the world for almost 30 years, aiming to run health care in a more efficient and citizen-oriented direction, providing political or citizen control over the services on behalf of professional hegemonies in the field (Hansen, 2007). According to Askheim (2012), in this perspective patients could be seen as individual customers using their strength or power to prioritize the services they wanted to achieve, and from which organization or level of care they wanted it delivered. Even in health care without liberalistic economic driving forces, discussions influenced by NPM have arisen with the aim of improving the facilitation of each patient’s requests and needs (Hansen, 2007).

The personal self-realization position of empowerment is present in the increasing amount of related literature and approaches in marketing and magazines. This dimension could be seen as part of the marketing approach in the empowerment context, but increasingly focused towards the inner self-esteem and authenticity of the individual, including in the context of health-related questions. “The Secret” is an example of popular self-help literature with a message about healing illness or remaining healthy through empowering oneself using mental and spiritual techniques (Byrne, 2006). Scientific articles also address patient empowerment outcomes such as self-esteem and experienced quality of life (Wehmeyer and Schwartz, 1997, Lachapelle et al., 2005, Samoocha et al., 2010).

In the therapeutic position of PE, individual care as a process should be in focus. The strengthening dimension is fundamental here, with the aim of changing the professional role from being determinant in the caring relationship to becoming a partner in dialogue on an equal footing. The patient's objective is to learn to master the situation and thereby to achieve control in life. Mastering and empowerment are closely related concepts (Askheim, 2012). Both individual and group-based techniques such as self-help groups are used by care professionals in order to assist patients to master their life and their illness or disability (Aglen et al., 2011, Kuijpers et al., 2013). In this therapeutic position, the dimension of power is underestimated, according to Askheim (2007). Empowerment is to a certain degree shifted from professionals to patients, with the expectation that patients will behave in a rational way by using their empowered situation according to the established standards of the care that is offered. Power is transferred from professionals to patients with certain reservations. (Laverack, 2005) states that to attain power is not so much an individual process as a collective process. Collective activities may then lead to political change. More articles underpin this understanding of the therapeutic position. The arguments of McAllister et al. (2012) regarding PE fit in here: by being empowered by the professionals in caring, patients can both maximize their health and wellness and be able to take rational healthcare decisions. They can then decrease their dependence on health care services and increase the efficacy of services being provided. A study discussing the relationship between patient-centeredness and patient empowerment proposes that professionals should increase their efforts to empower the patients to make the best choices about their health conditions (Holmström and Röing, 2010).

Even if patients are regarded as rational, autonomous, responsible persons capable of deciding on their needs for care themselves, it is acknowledged that patients will not be able to act in their best interests in all situations, due to various hindrances (Askheim, 2012). For example, people addicted to drugs may not always make their best choices for health care (Lima et al., 2009, Humerfelt, 2012). According to some theories of empowerment, these patients must be guided and helped to uncover their "true selves" in order to be able to make their best choices for their lives. This is also known from nursing theories as supportive or weak paternalism (Martinsen, 1991). This position has been criticized as sliding from well-intended information and education of the patient to enable further empowering to a paternalistic path, where professional guidance is influenced by the framework of the established and accepted values in the health care services, not necessarily in the direction that patients wanted or needed themselves (Askheim, 2012).

These criticisms of the empowerment concept may lead to yet another approach to patient empowerment: the emotional dimension vs. the rational one (Payne and Campling, 2005, Askheim, 2012). Payne and Campling (2005), state that PE is essentially a question of gaining control in life by rational and cognitive means, and through this, changing environment through similar processes. The emotional dimension might be seen as relevant in terms of the use of paternalism in empowerment, as this concerns the degree of emotional energy, shame and pride (Starrin in: Askheim and Starrin, 2007). This emotional energy is the patient's feelings in social settings, the degree of self-confidence or self-esteem, enthusiasm and vigour. The amount of vigour reflects the degree of emotional energy. The previously mentioned street-magazine seller can exemplify this. Besides being a counter-power example, it may be turned into a therapeutic context: if the person addicted to drugs gains improved pride and self-esteem by selling a street magazine instead of begging for money, the vigour and thereby the empowerment level may increase for this person. To go through an empowering process is thereby seen as a counter-power position but also as a therapeutic one: from gaining strength to gathering forces to obtaining mobilized power, or increased self-esteem and pride as the outcome of the process.

The concept of Patient and Public Involvement (PPI) has several approaches and definitions (Rise et al., 2013). Tritter (2009) defines the concept this way:

> "ways in which patients can draw on their experience and members of the public can apply their priorities to the evaluation, development, organization and delivery of health services"(Tritter, 2009).

Simces (2005) states that the concept of public involvement has been regarded for many years as a continuum of approaches and a variety of involvement levels and techniques used in order to reach these levels. Rise et al. (2013) have developed another definition in their study based on both service providers and service recipients:

> “Patient and public involvement is founded on mutual respect and is carried out through dialogue aiming to achieve shared decision making” (Rise et al., 2013).

Synonyms used in literature for “public involvement” are public participation, citizen participation or citizen involvement (Cornwall et al., 2003, Simces, 2005, Menon and Stafinski, 2011,Jones et al., 2012). Patient involvement” is also termed “client involvement” or “patient participation” (Cahill, 1996, Street et al., 2005, McWilliam et al., 2007, Thompson, 2007, Morris and Gannon, 2008). The “patient” and the “public” are discussed separately in various approaches, but some studies, such as those addressing the PPI concept, also include and discuss aspects across the individual and common level of involvement or participation (Forster and Gabe, 2008, Boivin et al., 2010). According to Tritter (2009), patient or public involvement including caring services can be classified into five main categories: (1) treatment decisions, (2) service development, (3) evaluation of services, (4) education and training of professionals and (5) the research cycle. The categories may all interact with and influence each other. These categories could all be used by individuals or as a collective approach in a community. Citizens or patients could also behave reactively as well as proactively or directly as well as indirectly in their individual or collective involvement strategies.

In treatment decisions, individual patients or, for example, patient interest groups may participate directly in terms of a specific treatment or treatment strategy. The patient as an individual could be more or less active in his or her specific treatment decisions due to the reactive or proactive dimension. In the service development category, there is more scope for patient groups to influence future services based on their knowledge, experiences and needs, or a patient could take part as a passive or active member of such groups. The same applies to service evaluation: both are traditional fields for citizen involvement, e.g. through politics. Political strategies or evaluations can be initiated or provoked by individual patients and their illness stories. Individual patients or patient groups have traditionally been objects for professionals in education and training, both directly as patients being questioned, examined or cared for by students in training for their future profession, or indirectly, as subjects for knowledge mining providing fragments of knowledge for further education.

What has changed in recent years, according to Tritter (2009), is the patient or citizen as a more active partner in the entire research circle. Patients increasingly take part as co-researchers, more or less informing the quality of the research results (Wright et al., 2006, Abma et al., 2009, Van Staa et al., 2010).

The PPI thinking is further related to the concept of citizen power or patient empowerment strategies through laws, patients' rights or stakeholder groups both for professionals and for citizens/patients involved. Care professionals, care bureaucrats and politicians at various levels in society are also potentially involved partners. These driving factors all add nuances to the picture of PPI.

3.3 Integrated Care in Norway: policy and implementation

Health care politics and structures in Norway were part of the development of the Scandinavian "welfare state" after World War II (Schiøtz and Skaset, 2003). The public sector and thereby the health care services in the Nordic countries were organized and run according to social democratic principles until the mid-1980s. Political reforms were introduced with requirements for increased communication and cooperation in multidisciplinary and cross-organizational care (Schiøtz and Skaset, 2003). New public management (NPM), as mentioned in chapter 3, was introduced and slowly gained a foothold in health care as an organizational approach aiming for collaboration, efficacy and output control in public services (Hansen, 2007, Busch et al., 2011). A further aim of introducing NPM was to add smart new ways to collaborate for improving quality and public service outcomes (Stamsø and Hjelmtveit, 2009). NPM as a governance strategy for health care in Norway has then influenced the integrated care approaches in our country (Holck, 2004, Hansen, 2007, Willumsen, 2009).

I have studied strategies and plans from governmental institutions in an effort to follow the path of integrated care in Norwegian politics. In 1995, a structural approach to integrated care developed through a governmental plan for rehabilitation. The report describing this plan referred to collaboration between the hospital and municipal level of care (NOU-1995:14, 1995). It also recognized the existence of organizational barriers to such collaboration. Patient involvement was not mentioned in the document. Governmental initiatives based on the principles of integrated care over the last 20 years culminated in the “Coordination Reform” (St.meld. nr. 47, 2009). The Coordination Reform required collaboration between the various instances of the health care system. Two years later, a governmental white paper on the national plan for health and care added details and presented, as stated in the abstract: “a policy for health care and public health for the following four years”. This document introduced legal, economic and organizational changes (St.meld. nr.16, 2010-2011).

3.4 The Individual care plan, a Norwegian approach to integrated care

The Individual Care Plan (ICP) is a Norwegian answer to both integrated care and patient involvement/empowerment. I first found ICP described as a concept for coordination of care in governmental documents in 1997: both a governmental white paper (St.meld. nr. 25, 1996-1997) and a consultation document in preparation for a Patients' Rights Act have chapters dedicated to the issue of individually adapted plans for patients. These documents led to changes in legislation from 2000 as part of a major health care reform, which also defined and, for the first time, named “Individual Care Planning” as a concept. ICP became a legal obligation in 2001 as part of the Specialized Health Services Act, the Act on Municipal Health Care Services and the Patients’ Rights Act (Kommunehelsetjenesteloven, 1982-2012, Spesialisthelsetjenesteloven, 1999, Pasient -og brukerrettighetsloven, 1999 / 2012). A specific administrative regulation for individual care planning (ICP) was introduced (Forskrift om individuell plan, 2001). ICP evolved to include social care services in 2005, and the change was introduced in legislation and regulations (Forskrift om individuell plan, 2005). The governmental regulation formalized new changes in 2011 in order to link rehabilitation more closely with ICP. Another aim was to highlight the coordination responsibility in a better way than previous legislation had done. Previous laws and regulations for rehabilitation were now merged with the ICP legislation (Forskrift om habilitering og rehabilitering individuell plan og koordinator, 2011).

From the start in 2001, the laws and regulation for ICP were a legal obligation for health care professionals in care planning, and in 2005 for social care professionals involved in patient care, in both municipal and hospital care (Helsepersonelloven, 1999, Spesialisthelsetjenesteloven, 1999, Kommunehelsetjenesteloven, 1982-2012). The link to the Patients' Rights Act ensured that patients were entitled to claim an Individual Care Plan in terms of specified criteria for eligibility (Pasient -og brukerrettighetsloven, 1999 / 2012). Recent changes in legislation influencing ICP should be seen as part of the Coordination Reform of 2009, aiming to improve continuity of care (St.meld. nr. 47, 2009, Heimly and Hygen, 2011). Individual care planning is defined as an overarching care planning process leading to a plan document. Both the regulation and guidelines from the Norwegian Directorate of Health gave detailed instructions for implementation and planning. The first guideline was published in 2001, followed by updates in 2005 and in 2010 due to changes in the legislation (Individuell plan, 2010). A new update was going through the consultation procedure in November 2014.

In international literature, there is a focus on various patient groups, classified by diagnosis or in specific parts of the health care system, that become objects for such integrated care systems (Leichsenring, 2004). The unique aspect of the Norwegian approach to integrated care solutions is the absence of diagnoses or care levels as a focus for the establishment of ICPs. The regulation states that all patients in need of long-term and coordinated care in health and/or social care are entitled to apply for a plan to be established (Kjellevold, 2002). Another unique approach in individual care planning in Norway and in the other Nordic countries is the involvement of the patient or user of care service as an equal partner in the care team (Humerfelt, 2012). The aim of the ICP as an integrated care solution is to assist patients who need coordinated and long-term care. A named coordinator is central in establishment and assistance functionality. Usually, a support team – a responsibility group (RG) – is established, headed by this named coordinator, for each individual patient. This RG meets together with the patient in order to establish and later on to conduct the care planning. In the planning process, mapping of needs and resources, goals and plan actions to be taken are all essential parts of the solution. Responsibility for carrying out actions is assigned to named participants in each RG, and the planning progress is evaluated regularly.

The ICP will be different, both as a process and as a document, for a child patient with autism and her parents than for an adult patient with schizophrenia. The variety of participants in the RG and the scope of the plan will be adapted to needs and life circumstances (Normann et al., 2004, Individuell plan, 2010). The coordinating role or "patient coach" has been described in even more detail in the regulation from 2011 than in the first regulation from 2001. Patients with long-term complex conditions and thereby the right to a coordinator, ICP, and rehabilitation are now coordinated according to law and guidelines (Forskrift om individuell plan, 2001, Forskrift om habilitering og rehabilitering individuell plan og koordinator, 2011).

As ICP was introduced as a statutory solution for integrated care in Norway, intensive efforts were made to organize the implementation. Care professionals, patients, patient organizations and local health care authorities were informed and trained in terms of a national initiative (Thommesen et al., 2003, Lidal and Røhme, 2006). After training, implementing projects and providing support from national expert centres, the Norwegian Board of Health followed up by checking whether the obligations had been fulfilled in municipality care and hospital care. Several reports showed that the ICP had not been implemented as expected or foreseen (Trefjord and Hatling, 2004). From 2006, all municipalities reported on the number of ICPs in their municipality. In the initial period, no such standardized reporting was required by the national authorities (IPLOS, 2009). A few studies so far have focused on ICP in Norway, and its information exchange between care professionals and sometimes also between patients and professionals. These studies describe ICP documentation in a paper-based way and communication channels as face-to-face meetings, postal letters and telephone calls. They all addressed limited success caused by various factors, but in general reflecting problems in both organizational cooperation and patients' contribution to care planning (Hansen, 2007, Humerfelt, 2012, Holum, 2012).

3.4.1 Implementation of ICT tools for integrated care strategies

I introduced definitions of integrated care in chapter 3.1, and showed that they had in common a multi-dimensional collaborative activity among care providers. Norwegian authorities established integrated care through individual care plan as political and organizational strategies. This is described in chapter 3.3.

Both theoretical definitions and political strategies have stressed the importance of communication and collaboration between health care actors to attain the target of integrated care. In practical terms, care providers need proper communication systems or tools to implement strategies for integrated care and individual care planning. Traditionally, communication to achieve integrated care through ICP took place in face-to-face meetings, telephone calls and postal letters or telefax (Thommesen et al., 2003). As new technological solutions have been developed, both the understanding of technological possibilities and the use of ICT tools to support integrated care have changed dramatically (Guldemond and Hercheui, 2012, Lluch and Abadie, 2013).

The first literature I found published focusing on ICT for clinical cooperation and information exchange within and between care institutions in Norway was Hjorth, (1989). In the following years researchers have described development and diffusion of the concept “telemedicine” in northern Norway, but also between hospitals or hospitals and general practitioners (GPs) in other parts of the country (Vorland, 1992, Aas, 2002, Larsen et al., 2003, Hartvigsen et al., 2007). These articles focused on telemedicine possibilities for increased collaboration, efficacy and quality of care (Aas, 2002, Ekeland, 2007). From the initial period of telemedicine, later named “E-health”, until today, ICT solutions have increasingly been introduced to strengthen multidisciplinary and trans-organizational collaboration in care (Haux, 2010, Heimly and Hygen, 2011, Melby and Hellesø, 2014). I searched for literature on patient participation and patient empowerment as a result of telemedicine or E-health communication tools in Norway. I found only a few publications. This might indicate that such focus on patient participation has so far have been given lower priority in the implementation of ICT tools for integrated care (Miller, 2001, Heimly and Hygen, 2011, Frøisland et al., 2012, Barberan-Garcia et al., 2014).

The first Norwegian governmental strategy for ICT in health care was introduced in 1997: “Mer helse for hver bIT” – “*More Health for each bIT*” (1996) focused on bridging health care initiatives, in particular on preparing for a national solution for a secure health network. This National Health network ambition was followed up by a second strategy for the following years: “Si @!” (“Say @h!”) in 2001 (Si @!, 2001). In this follow-up programme, the government’s focus was to realize the ICT collaboration over secure internet lines, a national health network between levels of care. The programme aimed to develop public access to health care and social service information through establishing secure ID certificates. In the longer term, the programme also aimed to provide opportunities for electronic communication between the public, general practitioners (GPs) and other unspecified health and social services. Secure communication was emphasized.

In 2004, when the National Health network was launched, a third strategy was presented for the following three years: “S@mspill 2007. Elektronisk samarbeid i helse-og sosialsektoren (Te@mwork 2007 – Electronic collaboration in the health and social care service)” (S@mspill 2007, 2004). The first priority in this strategy was to strengthen the information flow in the health and social care services, based on the previously mentioned Health network solution. Still, most of the proposals in the programme were in the context of how to offer general web-based access for health care information for professionals and their internal net-based communication. The second priority was to include new actors in addition to those already using the network. Here, one chapter referred to the involvement of patients, clients and next of kin and their use of ICT in connection with health care services. Chapter 4.1 in the strategy describes the lack of information access for patients, and the strategy in this programme is to offer electronic communication and dialogue when it is regarded as “appropriate and reasonable”. Patient organizations were now invited to participate in an advisory forum together with researchers and system vendors.

The next ICT strategy was “Samspill 2.0” (Teamwork 2.0), launched in 2007 for the period of 2008-2013. In the vision in this strategy, we hear for the first time about the integrated patient and user pathway through the use of electronic collaboration. The plan focuses on individual patient needs and collaboration as well as on increased quality and efficient care to support the professionals involved through improved information access and exchange through the secure health network. I referred to the Coordination Reform, a sovernmental trategy for integrated care, in chapter 3.3. This governmental white paper also made it clear that the standard way to communicate health care issues should be electronic, both between professionals and between professionals and patients. (St.meld. nr. 47, 2009).

In the same period, ICT implementation reached a level at which more than 80% of Norwegian municipalities had an EPR system to support care of elderly people (EPJ MONITOR, 2010). In late 2012, the Ministry of Health and Social Affairs launched a strategy to follow up both the "Coordination Reform" and "Te@mwork 2.0" – termed "One Citizen – One EPR" (St.meld. nr. 9, 2012). The Ministry of Health argued for a higher degree of national governance in order to establish a single cross-sectional patient record for each citizen, available to professionals involved in care. As stated as a goal in previous plans, according to this strategy citizens will obtain secure online access to monitor or retrieve information from their patient record. "The Summary Care Record" was a first legislative step towards a solution for shared EPR information, with a focus on how to share basic patient information between health care professionals across levels of care (Heimly and Berntsen, 2009, Lov om nasjonal kjernejournal m.m, 2012). This solution is still being tested in a pilot phase (Helsenorge.no, 2014b). The Summary Care Record is to be placed inside the national health network, and thereby inaccessible to patients themselves or to external care providers (ibid). The issue of electronic individual care planning was not a subject addressed by that law (Lov om nasjonal kjernejournal m.m, 2012). The legislation specifying patients' rights to access and receive transcripts from their EPRs was updated in June 2014. The existing laws and regulations governed the professional and institutional obligations regarding EPRs, provided instructions on EPR content, situation-based access, and needs for distribution.

The Norwegian Parliament approved two new laws in June 2014, being ratified in January 2015. These laws – the Patients' Record Act (Pasientjournalloven, 2014) and the Health Care

Registry Act (Helseregisterloven, 2014) – replace existing laws and regulations and elaborate the laws in the context of the planned national EPR solution: “One citizen, One EPR” (St.meld. nr. 9, 2012), which paves the way toward online EPR collaboration. ICP as a concept was mentioned, but not clearly expressed, in the white paper preparing for the new laws. The white paper also described briefly, in a minor section, the possibility of web-based communication between patients and professionals (St.meld. nr. 9, 2012).

Online exchange of patient information still takes place through partly structured messages such as admission notes and discharge summaries sent between partners inside the secure health network. Patient information is also exchanged in paper documents or by telefax between organizational levels in health care services (Bollig et al., 2010, EPJ MONITOR, 2010, Olsen et al., 2013b).

3.4.2 The gap between integrated care strategies and ICT strategies.

In the years of working on this research project, I have experienced gaps and obstacles due to governmental strategies and plans in relation to ICT tools and ICP.

Figure 4 shows a timeline for political ICT strategies, integrated care strategies and related laws and regulations in health care services. This timeline aims to sum up and visualize the gap between laws and strategies described above.

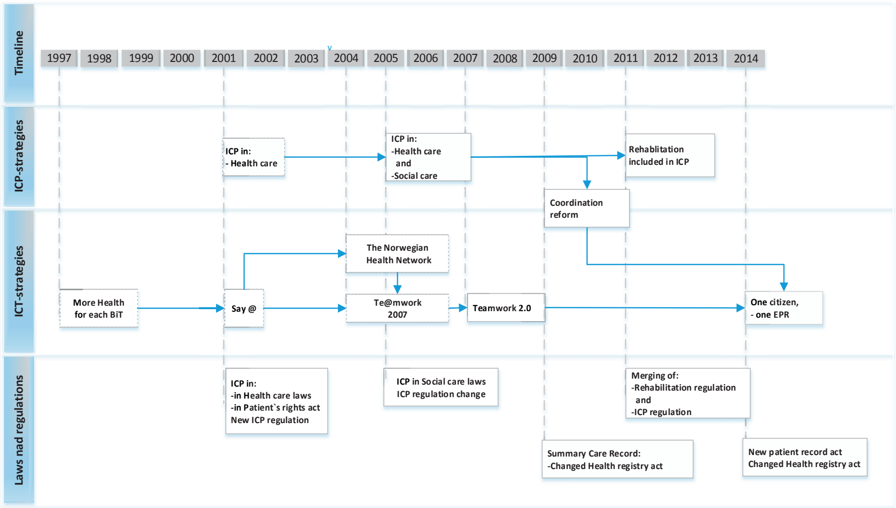

Figure 4. Timeline for ICP/ICT-planning and related legislation

Since 2003, government initiatives have called for online collaboration towards improvement of integrated care, but descriptions of how to implement ICT tools for integrated care have barely been mentioned. Neither do I find any political discussion on the subject. In the second ICP guidelines (Individuell plan, 2005) a minor chapter describes an e-ICP project, the case described in chapter 4.1 of this dissertation, as a possible ICP communication tool. In the 2010 version of the ICP guidelines, this information was removed. No other information on how to communicate ICPs is given in the document, and I find no other available information on existing legal restrictions for such web-based communication outside the secure health network (Individuell plan, 2010). An explanation may be a memorandum formulated by the Norwegian Directorate of Health in 2007 concluding that web-based solutions for communicating patient information such as individual care plans outside the secure Health network plans could *not* be implemented according to existing legislation for EPRs and patient information privacy (Castberg, 2007). Another example of this gap is evident in the treatment of a preliminary draft of the "S@mspill 2007" (Te@mwork 2007") strategy document issued as a consultation paper. This document included a paragraph on patients' access to their own health information:

> “Action no. 13: Access to your own health care information via the internet: discuss alternative models for giving patients access to their own health care information, aiming to establish net-based solutions”.

After the conclusion of the consultation process and the political debate, the governmental strategy was published with a different version of this sentence, which did not specify a particular direction (S@mspill 2007, 2004). The timeline was also extended: according to the preliminary draft, this Action no. 13 was to start early in 2005 and be realized in 2007, but a solution has still not been implemented. Other patient-related proposals in the 2007 strategy have now been realized, such as e-prescriptions and online appointments for patients to visit their GP (Fastlegeforskriften, 2012, Helsenorge.no, 2014a).

In the governmental white paper on the “Coordination Reform”, previous years of effort towards integrated care are evaluated as unsuccessful. Previous strategies had not realized their ambitions (St.meld. nr. 47, 2009). This reform corresponded in time to the Samspill 2.0 strategy, which aimed to consolidate and realize previous ICT visions (Samspill 2.0, 2007). Electronic communication of health care issues as a standard way of sharing information and knowledge was a main target in both these strategies, but far from the reality when the strategies were introduced. Hindrances still present were legal, organizational and economic factors, which all had to be addressed (Samspill 2.0, 2007, St.meld. nr. 47, 2009). One of three main challenges highlighted in the Coordination Reform document is that the patient’s needs for coordinated services have not been sufficiently met so far. The document focused on both technological and organizational challenges in order to solve these problems. A plan was developed for the Government to evaluate legislation addressing continuity of care (St.meld. nr. 47, 2009). The shortcoming is underpinned by research projects on integrated care initiatives in Norway, also described in ch. 3.4: the practice of integrated care initiatives has had limited success so far (Holck, 2004, Hansen, 2007, Holum, 2012). Participation and empowerment among e.g. patients with drug addiction who have an ICP has still not reached the desired level of practice (Humerfelt, 2012). Another example is that integrated care in the form of information exchange between home care and hospitals for elderly patients has proved to be limited both in content and quality (Olsen et al., 2013a). The results from these research projects indicated good intentions but lack of outcomes reflecting high quality and efficient coordination or integration of care according to the concepts of NPM and patient empowerment or involvement.

An OECD review on Health Care Quality in Norway focused on shortcomings in integrated care (Hewlett et al., 2014). The review includes assessment of both the Coordination Reform and ICP, but it does not assess patient participation: with few exceptions, patients are referred to as service recipients. The review includes several recommendations on measures towards reaching the desired level of health care quality, such as more consistent use of ICPs, and improvement of information transmission between providers. The review suggests extending the use of ICP so that patients with "severe and enduring mental disorders" can access their plan together with their care providers. Here, the OECD review argues for active patient participation. The OECD review also draws attention to the lack of ICT platforms as a factor explaining poor coordination and integration of care planning (ibid).

Laws and regulations dealing with patient information security and privacy have changed little in the period during which integrated care solutions, in particular the ICP, and ICT solutions have emerged in Norway. Even if laws and directives on ICPs were introduced and refined, no adjustment in the laws regarding privacy concerns was seen. This restricted the use of web-based solutions for the purpose of collaborative tools creating the potential for care planning including patients and participants outside health care domains (Barberan-Garcia et al., 2014). The content of the white paper "One Citizen, One EPR", which was already reflected in changes in laws, shows ambitions towards bridging the gaps described in this chapter (Prop.72 L, 2013-2014, Helseregisterloven, 2014, Pasientjournalloven, 2014).

When the new laws of 2014 take effect, we will learn how the new laws will be interpreted in practical solutions. How these laws will be combined with legislation such as the law and administrative regulation describing the Summary Care Record remains to be seen. Whether it will be permissible only to distribute patient information to patients and not to exchange such information with patients or with other actors outside the secure Health network also remains to be seen. The white paper “One Citizen, One EPR” (St.meld. nr. 9, 2012) states that the ambition of a fully integrated patient record including patient participation will take years to establish, and detailed plans are not presented. Web-based communication with professionals outside the health care environment, as required in ICPs, is not described. Neither is the possibility of involving patients and the public through active documentation clear. The white paper focuses on patients more as readers of their EPR (Prop.72 L, 2013-2014). Another gap between the ICP and the new EPR law is that ICP requires active consent (Kjellevold, 2013). In contrast, the new Patients’ Record Act (2014) provides for passive consent, familiar from previous EPR legislation (Pasientjournalloven, 2014). This may leave a gap between the legislation and the potential functionality of ICT tools.

4 Study context and organizational setting

Municipal health and social care services in Norway were chosen as the context for the first study, study I, to provide answers about the implementation and use of ICP. We continued in study II by following a system testing and implementation project. The purpose of this testing project in study II was to develop an ICT tool for the Central Norwegian Region Health Authority (CNRHA) and public at large to provide digital support to ease and improve implementation of individual care plans (ICPs). The Central Norway Region Health Authority trust (CNRHA) stated that the hospital trust had experienced a lack of efficacy and quality of care in individual care planning in the paper-based initiatives. They found no ICT systems available that could communicate ICPs to participants outside the National Health Network solution. EPRs including modules for ICP were only accessible to professionals inside each institution. RG members outside health care institutions were not admitted to this secured portal. Such members included schoolteachers or pre-school teachers, social workers or welfare officers, and indeed the patients themselves and their family members.

The health trust requested new solutions for ICP among potential participants via secured encrypted communication. Examples of such participants included professionals communicating inside the Health network or professionals, lay participants or patients who were excluded from this network. The health trust initiated and established an OFU-project[1] for development, testing and implementation of a web-based tool for ICP: the SamPro project. This became the context for study II. SINTEF, a Norwegian research organization, was involved during the initial period for system specification and prototype development (Walderhaug et al., 2006). Visma inc. was the joint vendor.

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[1] OFU project: A public research and development project involving commercial companies together with public services.

The test sites of this study were:

Site 1: County 1: two town municipalities, one rural municipality, two affiliated hospitals

Site 2: County 2: one city municipality, one affiliated hospital

Site 3: County 3: one town municipality, one affiliated hospital

The PhD project started as a research component of this project as testing of the application was about to begin. The PhD candidate was engaged part-time as the regional project manager of the SamPro testing project. In addition, the three local project leaders, a system vendor representative and a patient representative joined the regional project team. According to the SamPro project plan, the system was to be tested and developed in real RGs using the tool for ICPs in which participants were involved. This activity could be from their homes, in municipality health and social care units, or from the affiliated hospitals. The SamPro project entered as one of three pilot partners in an EU project, in the eTEN – eHealth Programme "LINKCARE: Linking Health Professionals in Emerging Care Environments". SINTEF had the technological responsibility in this project (Garcia-Aymerich et al., 2007, Mikalsen et al., 2007, Pitsillides et al., 2007, Bjerkan and Alonso, 2010).

4.1 The SamPro testing project

The ambition of this project was to achieve national goals for ICP through development and testing of a web-based tool, SamPro. The results were intended to help in the further development or adjustment of the solution. This chapter partly relies on information from CNHRA internal project documents and reports.

SamPro project documents showed that system testing had not proceeded according to the project plan (Bjerkan 2005, Bjerkan, 2006, Bjerkan, 2008, Hollingen, 2008). The testing phase started 9 months behind schedule and ended without achieving the planned testing and development results. Establishment of testing groups and system training took longer than expected. New phases were then established. Phase 2 and phase 3 were extended by 14 and

12 months respectively. Unexpected obstacles to testing as well as reorganization in the vendor company and in the SamPro project organization contributed to the delays. The project phases are shown in figure 9 in the Results chapter.

SamPro was an early pilot permitted to handle sensitive personal information over the internet. A balance between accessibility and an acceptable security level was essential: a popular module for document filing had to be withdrawn due to statutory restrictions, (Bjerkan and Alonso, 2010). Printout functionality also had to be encrypted and logged. The distribution of passwords via mobile phones and SMS – a new solution at that time – was implemented. Unfortunately, this “bleeding-edge” technology caused unforeseen SMS routing delays that prevented users from accessing the system. Even if testing activity increased in phase 2 and SMS routing was improved, participants criticized low development effort and delays in system deliveries and problem solving (Bjerkan, 2005).

The testing project was split into three parallel tracks in phase 3 as shown in figure 9:

A. Completing development and testing through phase 3.
B. National dissemination of the SamPro system.
C. Participating as one of three European pilot sites in an EU project, Linkcare.

The project team completed a system assessment session through a questionnaire that included both project-specific questions and elements from validated questionnaires (Davis, 1989, Brooke, 1996, Venkatesh and Davis, 2000). Responses showed that frequency of use was concentrated at an average level (now and then). User satisfaction scores showed a coherent score at 61 in a range from 0-100 (Bangor et al., 2009, Bjerkan and Alonso, 2010). Technological acceptance questions confirmed this result being at a mid-level of acceptance (Roca et al., 2007).

The closing reports from the project (Bjerkan, 2008, Hollingen, 2008) showed both goals achieved and goals missed in relation to the interests of the participants involved:

- A PKI- (Public Key Infrastructure) solution for log-on procedures was postponed by the authorities and therefore not implemented as planned. Instead, an encrypted distribution of passwords via mobile phones was introduced, as described above.
- An alternative log-on procedure was developed for care professionals who did not have, or did not want to use a personal mobile phone for log-on identification.
- A detailed access module with fragmenting possibilities was developed and implemented. Neither care professionals nor patients expressed concerns about lack of system security, or about system access for patients.
- Limited access to PCs at work was reported, which delayed system testing.
- A possibility to hide phone numbers from the system interface was introduced as an answer to care professional's demands. They were concerned about disclosure of their private mobile phone number, and some were concerned about the possibility of receiving SamPro SMS alerts while they were off duty. No solution to prevent SMSs in off-duty situations was found during the project period.
- Improved functionality for documentation tasks, such as adjustable printouts and filing structure was implemented.
- The complexity of integrating documentation systems such as electronic patient records (EPRs) into SamPro was not carefully considered. This was also hindered by statutory restrictions. On the other hand, care professionals did not prioritize information exchange between the SamPro system and patient EPRs or other user-documentation systems.
- SamPro was not realized as planned as a tool to support ICP as a national indicator for quality of care and with functionality to extract control data for municipal management.
- The SamPro system was specified as the preferred e-ICP tool in the affiliated hospitals, but the ambition of system dissemination in the municipalities was not met: only a handful implemented the tool for ordinary use.
- The LinkCare project developed a prototype for a European portal for chronic care using elements from the SamPro system architecture (Roca et al., 2007). Due to legal restrictions, this portal was not introduced for Norwegian patients.

5 Methods

This chapter presents an overview of the methodological approaches used in this research. The research project included two studies applying both quantitative and qualitative methods to answer the research questions in chapter 2.

5.1 Analytical framework

My focus in this research project was *user* participation, here in the sense of *ICT users* – both care professionals and patients. This approach was influenced by both participatory action research (PAR) from social science and in particular participatory design (PD), also known from computer science theory.

I find conceptual overlaps in the literature between the terms “action research”, “participatory action research (PAR)” or “participatory research”, and “participatory design” (PD), (Neuhauser, 2001, Barab et al., 2004, Jansson et al., 2008, Malterud, 2011, Bannon and Ehn, 2012). The various concepts are commonly founded on political and ideological movements in the post-world-war period in Europe and the USA: both Lewin (1946), and Freire (1970), are examples of researchers who influenced a movement against the established elitist hierarchical system in research and politics towards a more democratic and inclusive philosophy (Holmer and Starrin, 1993, Malterud, 2011, Kensing and Greenbaum, 2012). In political terms, these ideas are related to the concepts of patient empowerment and the PPI concept addressed in chapter 3. Like both PPI and patient empowerment, these ideas aim to arrange for the patient to take an active or leading role in his or her own health care.

I summarize characteristics and outcomes of AR, PAR and PD this way:

Table 2. Characteristics of AR, PAR and PD methods

Method	**Characteristics of the method**	**Participant Outcome**
Action research (AR)	The researcher: at a scale from observer to agent of change The research field participants: from well informed to active influence	Political change Empowerment Pragmatic result
Participatory (action) research (PAR)/(PR)	The researcher: treating participants as "co-researchers" The research field participants: from being comfortable to determinant	Political change Empowerment Pragmatic result
Participatory design (PD)	The researcher: arranges for user participation in iterative design cycles The research field participants: from no involvement to co-realization	Political change Empowerment Pragmatic result Economic interest

5.1.1 Action research

I do not find any clear consensus on a definition of "action research" (AR) in the literature. I understand this concept not strictly as *one* static dimension of the qualitative research, but more as an umbrella concept covering a family of approaches as described in the preface of Reason and Bradbury (2008). AR as a research concept may aim not only to observe, but also to be an agent of change in relation to the subject being researched, and the research team may be involved in that changing process (Reason and Bradbury, 2008). The degree to which participating groups are involved and the way in which they participate may vary. According to Holmer and Starrin (1993), participants in AR research projects should at least be well informed about the research progress. In an ICT testing project participants testing the software could just commit their testing tasks, and be passive, but informed objects of a research project following the system testing. The opposite position could be if system-testing participants actively influence the research process or progress by their ideas, attitudes or actions.

5.1.2 Participatory action research

This PhD project could further be placed under the action research umbrella in the context of “participatory action research (PAR)” or “participatory research”, (PR) which Borda refer to both as separate terms and as synonyms in Reason and Bradbury, (2008). I chose the term “participatory action research” in this assembly of methodological theoretic approaches, being aware of the crossover between PAR and PR. In contrast to traditional observation studies, the researcher role in PAR projects is not that of an observer, and the public is not being observed as subjects of research. In PAR both parties – the researcher and the public involved – participate on equal terms to obtain results (Whyte, 1991, Malterud, 2012, Polit and Beck, 2013). Participants are involved more directly in the research project. They are more clearly included, even determinant as co-researchers compared to other action research approaches. (Whyte, 1991). This calls for methods and attitudes from the professional researchers that support and facilitate such a co-researching role (Holmer and Starrin, 1993). The results from a PAR process could be both political and empowering (Borda, 2001, Kelly, 2005, Park, 2006, Polit and Beck, 2012). PAR research projects can also take a more pragmatic direction besides the political and empowering approach described above. This depends on the results aimed for in the research project, whether an empowerment change is desirable, or whether participants were involved only because of convenience (Holmer and Starrin, 1993).

5.1.3 Participatory design

This research project involves ICT systems, and my technological understanding was influenced by the theory of participatory design, (PD) (Bødker et al., 2011). One definition for PD is:

> “an approach to development of technical and organizational systems that places a premium on the active involvement of potential or current users in design and decision-making processes” (Trigg and Clement, 2000).

A model for the PD cycle was presented by Bratteteig et al., (2012):

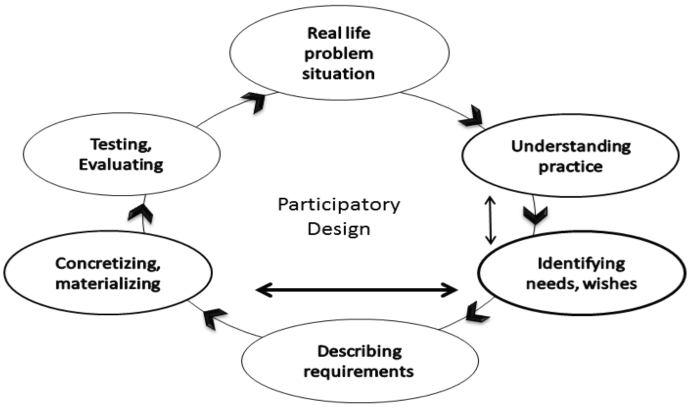

Figure 5. A use-oriented design cycle in PD. (Adapted from Bratteteig et al., p 128, 2012)

PD as a research approach follows different traditions or directions parallel to the two-way approach in PAR described above: one direction emphasizes the inclusion and empowerment of end users, while another direction has been regarded as having a more pragmatic or economic focus, aiming to add the best information to achieve a successful result (Asaro, 2000, Bergvall-Kåreborn and Ståhlbrost, 2008). The political direction, also called “the Scandinavian tradition of PD”, was developed in the early 1970s empowering industrial employees through influencing system development in their work environments. The pragmatic direction of PD, termed JAD (joint application design), was introduced in the USA: here, the aim of the organizational learning process and product development through participation in system development was to improve results and the outcome for the participants involved. Political influence and power were not fronted in the same way as product results (Asaro, 2000, Simonsen and Robertson, 2012).

A further perspective on PD is the *degree* of user participation: from no involvement, progressing in four steps to a state of strong control, with a direct financial interest in both the risks and income associated with development (Ives and Olson, 1984). This corresponds to the levels of involvement in PAR described earlier in this chapter. Degrees of participation are also determinant for the level of “having a say”, possibilities of “mutual learning” and “co-realization”, which are yet another perspectives in the PD-family and may be seen more as the political empowering direction of PD (Bratteteig, 2012). To have something to say at a basic level of PD depends on the possibilities of being heard, which implies a (political) strategy among participants involved in system development. “Mutual learning” as a core element in PD depends on arrangements that develop a relationship among the participants. This is also described as a learning environment. An example could be that initially unequal participants in a research project use PD to work towards having mutual respect for each other in order to start collaborating in research. Having a level of confidence through mutual respect, participants might be able to learn from each participant in the project in spite of initial roles such as being a patient, a care professional or a researcher.

The co-realization perspective is the design involvement in itself where elements such as technological artefacts are presented to the research participants. These presentations must be understandable and transferable to future use, typically close to real-world presentation in a lab setting, or a pilot application for testing. Participants may now understand the technology and be involved in decisions towards further development of the tool (ibid).

5.1.4 PAR and PD applied to SamPro system testing

This thesis focuses on groups of people that might be regarded as groups with challenges: psychiatric patients and parents of children with disabilities. These patient groups are well suited to adaptation of both the theory and the method of participatory action research (PAR) according to the political concept of PAR. The political concept of PAR corresponds to the empowering idea of ICP focusing on patient groups with long-term illness or disability. In the pragmatic context, these patients have had long experience of their disability or illness, which enables them to supply both the research project with well-founded reflections and statements, and the system vendor with valuable information for development of the system for future end-users.

Participatory design –PD- as a theory known from technological research also became a natural choice in this research project: PD facilitates strong end user participation throughout the entire development and testing process (Muller, 2003, Bødker et al., 2011). Figure 5 represents an iterative and broad-based approach to the PD process and underpins the understanding of PD in this thesis, which focuses on the entire system development process including system testing, not restricted to the prototype design level (Gulliksen et al., 2003, Muller, 2003, Pilemalm and Timpka, 2008). Both the pragmatic and the political scope of PD described above were regarded as being relevant in this research project. The system vendor wanted a successful ICT-system for commercialization after the testing period, and the vendor’s approach to PD theory in testing was the pragmatic one. On the other hand, the political influence from the ICP idea about patient participation and patient empowerment invited a setting of collaboration among a wide range of participants, and thereby system testing in the RG groups.

5.2 The overall research design

Study I was regarded as a pilot study to increase knowledge in the field of ICP. The main study was study II. Figure 6 illustrates the two studies, the methods applied, the context and the articles to which they relate.

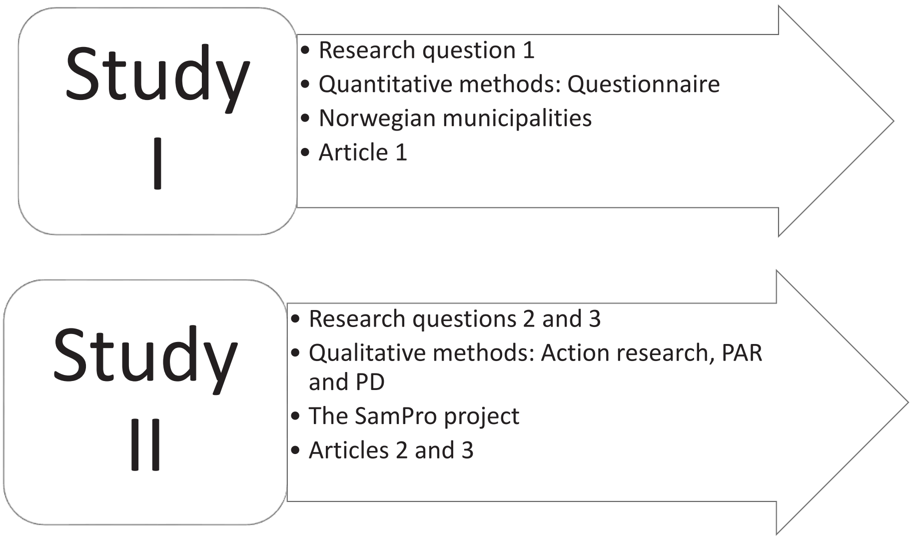

Figure 6. Studies in this thesis

I adopted a two-step approach because at the start of this project I had found little research published that was relevant to the Norwegian ICP solution. Nor did I find research that addressed electronic systems for ICP or other similar web-based collaboration between patients and care professionals in the same national setting. We regarded this research project as a pilot for obtaining insight in the field.

Study I aimed to characterize and describe the implementation and use of solutions for ICP in Norwegian municipalities. In this study, we initially investigated the field of ICP in Norway by collecting experiences from ICP work by professionals in the SamPro project from its early design phase. We investigated documents from the initial SamPro system specification and prototyping phase and we read available literature and reports on the topic (Normann et al., 2004, Trefjord and Hatling, 2004). We conducted an internet search for the Norwegian phrase "*individuell plan*" (individual care plan) to gain a wider impression of the distribution and use of ICP. We searched for related solutions in other European countries, focusing on Scandinavia (Gröne, 2001, Crawford et al., 2002,Psykiatrien i Nordjyllands Amt, 2003, Leichsenring, 2004). We chose a questionnaire survey as the method for this pilot study because we found this to be an efficient and reliable method for securing the data we needed in the pilot stage of the research project (Polit and Beck, 2012).

Study II was regarded as the main study in this thesis, incorporating knowledge from pilot study I. We chose Action Research (AR) as the overarching methodology in study II and included methodological theories from Participatory Action Research (PAR) and Participatory Design (PD), as presented in chapter 5.1 (Kelly, 2005, Simonsen and Robertson, 2012). We wanted to use the AR because the context of Study II was the SamPro system testing and implementation project used as a tool for ICP. The SamPro project implemented the national ICP strategy, with patient involvement and collaboration among involved participants, care professionals and patients as a main focus and success criterion. We demonstrate the implementation of PAR and PD methodology in the study flow and data collection part later in this chapter through examples of how we implemented PAR and PD in testing.

5.3 Material and participants

5.3.1 Study I

We found no validated questionnaire suitable for the purpose of study I in the international literature, so we developed a questionnaire to answer the research question 1 based on initial activities as described above. The questionnaire was piloted by sending it to a selected number of care professionals in municipalities in the mid-Norway region. We made no major changes resulting from the responses. We created two variants of this questionnaire: one for large urban municipalities, which were asked to obtain answers for one district of the city, and one for other municipalities, which were asked to cover the entire municipality in their response. The content of the questions was identical.

Table 3. Municipal sample for questionnaires in study I.

Municipality size	Population of the municipality	Number of municipalities in the sample
Small municipalities	< 5000	47
Medium-sized municipalities	5000-19,999	30
Large municipalities[1)]	>20,000	16

[1)] Including internal city districts for two city municipalities in the material

Table 3 shows the sample of municipalities randomly chosen for receiving questionnaires. The municipalities which we chose as respondents for the questionnaire were asked to find a suitable health care manager or municipal officer themselves to answer our request.

Appendix 1: municipal questionnaire in study I.

5.3.2 Study II

We included participants and collected material from the SamPro testing and development project in mid-Norway in this main part of the PhD project. When this study started, the system had been designed, developed, and tested in the laboratory. It was now ready to be implemented and tested by ordinary system users: care professionals and patients. The testing sites were established in all three counties included in the region, which were all covered by the mid-Norway hospital trust. Local project managers in the three testing sites recruited adult patients and child patients represented by their parents to the system-testing project according to inclusion criteria listed below. Diagnoses or types of illness are not included in the general ICP criteria, but we learned from available literature and reports that there had been a focus on establishing ICP activity in psychiatric care and in child rehabilitation. General geriatric care or cancer care could both have included relevant patient groups in need of integrated care and entitled to an ICP, but they were not represented among the strategic initial groups (Trefjord and Hatling, 2004). As a result, we searched for potential participants to include in the study among patients with psychiatric illness and children in need of rehabilitation services. We therefore defined these groups as part of the inclusion criteria. We recruited care professionals as members of the included patient's RG. RGs were established after joint assessment of the case with a person responsible for ICP management in each participating municipality. Requests were based on criteria for participation and interest in participating in the testing.

Table 4 shows the number of adult patients, their relatives and child patients represented by their parents included in testing.

Table 4. Patients and relatives involved in SamPro system testing and development

	Patients	**Relatives**	**Parents**	**Total**
Adult Psychiatric patients	54	10		
Child patients	(22) [1)]		43	
Total	54 /(76) [1)]	10	43	107

[1)] Represented by their parents

RGs for adult patients included an average of three persons: the patient, the coordinator and one or two other professionals. Apart from three patients who coordinated their own plan, coordinators were mainly nurses, most of them with specialized education and training in psychiatric nursing. One plan was coordinated by an occupational therapist[2] and one plan by a social worker. Table 5 shows the number of professionals and distribution among professions involved in SamPro system testing.

Table 5. Professionals involved in SamPro system testing and development

	Nurses	Social workers	GPs	Psychiatrists	Occupational therapists	Physiotherapists	Psychologist	Case managers -Employment service	Teachers	Total
Adult patients	63	7	1	3	1		1	1		77
Child patients	16	14	4		12	14	3		18	81
Total	79	21	5	3	13	14	4	1	18	158

Groups for child patients in need of rehabilitation who joined the system-testing project typically consisted of 5-7 participants, where the key actors were the parents representing their child and the RG coordinator. In addition, these RGs consisted of professionals from a wide range of municipal and hospital services groups, as presented in table 5. The role of coordinator in the groups for children was often assigned to nurses or case managers in treatment units who had varying professional backgrounds in health and social care. Coordinators of these groups also included two teachers, one occupational therapist and one social worker.

These were the inclusion criteria for participating in the SamPro system testing:

1. Inhabitants in the five selected municipalities in mid-Norway who lived in their own or their parents' home.
2. Adult patients/child patients who had the right to an individual care plan prepared in accordance with the relevant laws and regulations because they needed a combination of long-term services in connection with a chronic illness or permanent disability.

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[2] An occupational therapist has a bachelor’s degree in occupational and daily life training, often working together with physiotherapists

3. Children and young adults under 20 years of age with disabilities and adults over 20 years of age with serious psychological illness who received health and social care services.
4. Access to and willingness to use a PC with an internet connection in the preparation and maintenance of a plan.
5. Own mobile telephone or personal email address for the log-on procedure and receipt of messages from the application.
6. Established responsibility group consisting of at least two persons: a coordinator and the patient or the patient's parent.
7. An appointed plan coordinator with the responsibility for planning and who was willing to participate in testing.

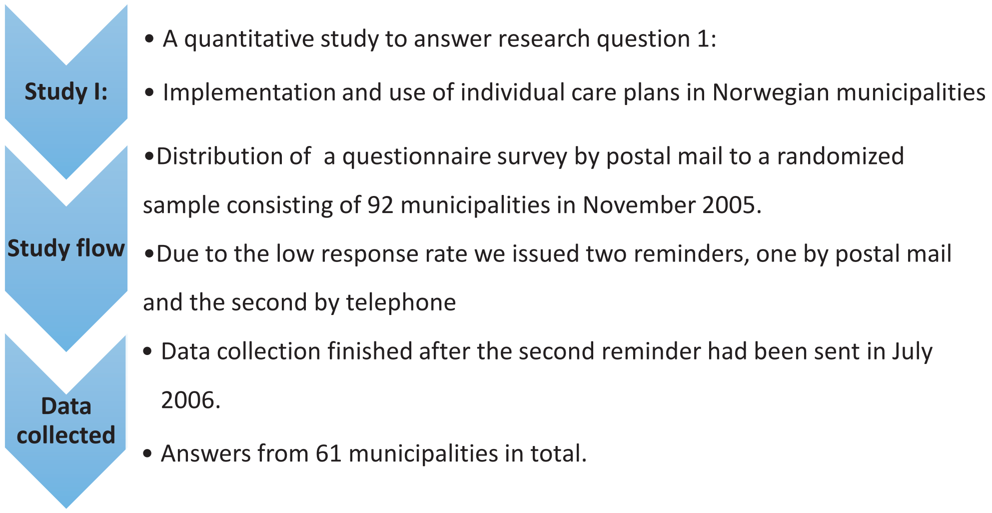
These were the exclusion criteria for participating in the SamPro system testing:

1. For professionals: no possibility or no desire to use a PC with an internet connection for registration and maintenance of the plan in a responsibility group.
2. For patients/parents: no PC and/or internet connection possibilities, anxiety about use of the internet in connection with one's own personal information, lack of interest in participating in the trial.

5.4 Study flow and data collection

Both qualitative and quantitative methods were used in this research project, as illustrated in figure 6 in chapter 5.2. The two studies thus involved various approaches in terms of both study flow and data collection methods.

5.4.1 Study I



Study I:

- A quantitative study to answer research question 1:
- Implementation and use of individual care plans in Norwegian municipalities

Study flow

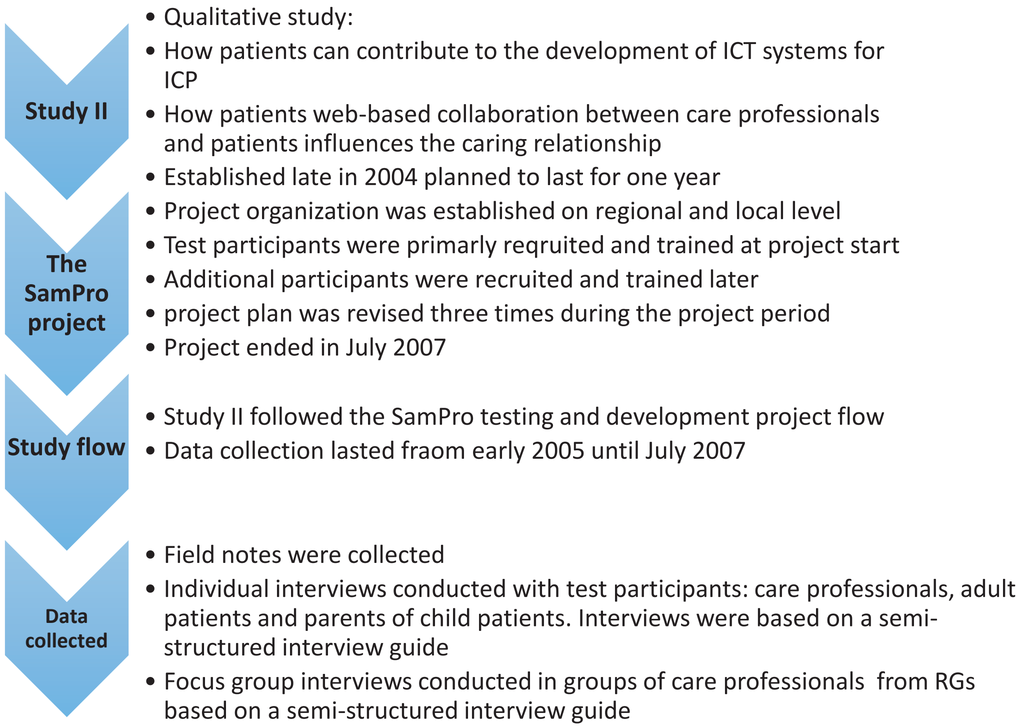
- Distribution of a questionnaire survey by postal mail to a randomized sample consisting of 92 municipalities in November 2005.
- Due to the low response rate we issued two reminders, one by postal mail and the second by telephone

Data collected

- Data collection finished after the second reminder had been sent in July 2006.
- Answers from 61 municipalities in total.

Figure 7. Study flow and data collection in study I

5.4.2 Study II



Study II

- Qualitative study:
- How patients can contribute to the development of ICT systems for ICP
- How patients web-based collaboration between care professionals and patients influences the caring relationship

The SamPro project

- Established late in 2004 planned to last for one year
- Project organization was established on regional and local level
- Test participants were primarly reqruited and trained at project start
- Additional participants were recruited and trained later
- project plan was revised three times during the project period
- Project ended in July 2007

Study flow

- Study II followed the SamPro testing and development project flow
- Data collection lasted fraom early 2005 until July 2007

Data collected

- Field notes were collected
- Individual interviews conducted with test participants: care professionals, adult patients and parents of child patients. Interviews were based on a semi-structured interview guide
- Focus group interviews conducted in groups of care professionals from RGs based on a semi-structured interview guide

Figure 8. Study flow and data collection in study II

Appendix2: Interview guide for study II.

The SamPro system introduced new solutions that had not previously been tested in connection with web-based communication in health care. We experienced challenges because of the gap between the intentions for ICPs and the provisions of current legislation as I have described in chapter 3. This influenced the study flow.

5.5 Data analyses

5.5.1 Study I

In Study I, we analysed data from the questionnaires using SPSS version 16. Two persons participating in handling of the material controlled data entry and analyses. We produced frequencies, correlation tables and regression analyses based on the data material.

5.5.2 Study II

We analysed individual interviews, focus group interviews and field notes using Systematic Text Condensation (STC). We followed the method described by Malterud (2001). This approach to STC also allows for the use of original quotations from the text instead of constructed quotations to describe themes. Original quotations from interviews were used in this research. In addition, not all data were included in the final themes, as related methodological approaches describe (Giorgi, 1985). Parts of the quotations from interviews or sentences from field notes that we did not regard as relevant were set aside (Malterud, 2001).

6 Ethical considerations

The research project was approved by the Norwegian Social Science Data Services (NSD) and reported to the Regional Committee of Medical Research Ethics (REK) in mid-Norway. Participants involved in Study II received both oral and written information about their participation in the project. All patients or parents of child patients in the pilot testing project were asked to sign consent forms for participating in the research part of the project. For RGs and patients who wanted to continue using the e-ICP as their tool for ICP after the testing phase and project ended, arrangements were made to ensure that they could do so, even if they wanted to withdraw from the research part of their project participation. Post-project continuity of system use was assured if their home municipality chose not to continue with the SamPro system for ordinary use. Permission for professional participation was given by municipal management and from the hospitals on behalf of staff.

Appendix 3: approval from NSD and REK.

Appendix 4: letter to testing participants in study II.

7 Results

In this chapter, a summary of the research is provided:

- Study I has paper I as output.
- Study II has papers II and III as output.

The two sub-studies in this PhD project and the SamPro testing project were closely connected, as figure 9 illustrates. Figure 9 shows the information flow and connections between the SamPro project and the PhD project presented in a timeline. Processes and relationship lines illustrate the period of time in which either of them were active, not the volume or size of each of them.

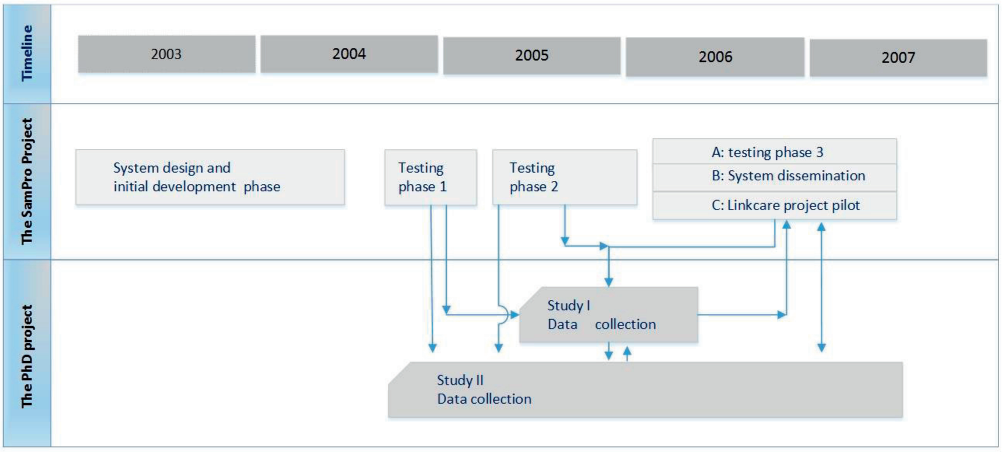


Figure 9. The SamPro project and the PhD project: timeline and interconnections.

The interaction with the SamPro testing project presented in chapter 4.1 was tighter than just using the system testing as an observation area for a research project. The testing process in the SamPro project benefitted from the ongoing data collection from both sub-studies in the PhD project and preliminary research results were brought back to the testing sites for further system improvements.

Results from the system design and development phase and from the initial part of system testing were used in preparing the questionnaire for the PhD study I. In the next phase, preliminary results from Study I informed both the SamPro testing project plan for the latter phases of testing and the data collection and thereby the results of sub-study II of the PhD project.

7.1 Study I

Until 2005, little research had been published to evaluate the results of governmental initiatives to promote ICP in Norwegian municipalities. Study I provided information about how municipalities managed the use of ICP: who participated in the ICP work and in what way, as well as how they documented and communicated the planning. This informed the SamPro system testing but was also used to develop the questionnaire in study II.

7.1.1 Summary of aims and results from Paper I:

Title: Integrated care in Norway: the state of affairs years after regulation by law.

In this paper, we explored the implementation and use of ICP in Norwegian municipalities. We also investigated additional factors that might influence the deployment of individual care plans: the size of the municipality, local political dominance, financial situation and living conditions in the municipality.

We found that one in 200 citizens (0. 5 %) had an individual care plan. The proportion was much lower than the figure of about one in 33 (3 %) reported in the governmental white paper estimate (NOU 2004:18, 2004). Although fewer patients or users than expected had an ICP, the result showed that those who did have an ICP were actively engaged in their own care planning. The result also provided organizational insight into how municipal health and social care services collaborated with patients and other care professionals as well as external institutions providing care. The number of established ICPs in each municipality proved to be independent of factors in our analysis. Whether the municipality had a conservative or social-democratic majority in its municipal council was not associated with significant differences in the numbers of plans or the way that ICP was organized. Neither did the social or financial situation in the municipality make a difference in the use of plans.

Municipal nurses, teachers and social care professionals qualified at bachelor’s degree level performed most of the ICP work. These professionals initiated new ICPs, implemented activities described in the ICP and coordinated the work of others. Hospital staff and GPs contributed less. They rarely took the initiative for new ICPs, or responsibility for the planning process.

This study was undertaken during the transition from a period of paper-based documentation and communication towards a digital one: more than half the respondents always or often used software to document the plans, 26% often used specialized systems for ICPs, and 13% used modules in EPR systems. Handwriting was still used frequently by 23% of the respondents. Professionals in the municipalities communicated ICP tasks mainly in physical meetings, but also by telephone. E-mail ICP communication was seldom used, but 2% reported that they always or often communicated ICP data through e-mail correspondence. This information provided important insight for answering the research question of how the ICP fulfilled its intentions according to law and regulations. We concluded that the objectives for the legislation on ICP were not being achieved satisfactorily: few patients entitled to a plan actually had one, and plan responsibility among care professionals and care institutions was unequal.

7.2 Study II

This action research study was the main part of the PhD project following the SamPro system testing in the Central Norway Region Health Authority (CNRHA).

Study I confirmed that municipal organization or politics did not correlate with the dissemination and use of ICP. It also showed which professionals were directly involved in ICP work. These signals were valuable for the SamPro testing project: the focus should be on persons involved in the testing activities instead of on municipal organizational differences at the testing sites. Organizational information on ICP was important mainly for practical reasons. Insights into plan documentation routines and plan communication structures were used in system improvements and system testing. The result from Study I showing types of user involvement in ICP work was then used in the development of the interview guide in study II.

7.2.1 Summary of aims and results from Paper II:

Title: Patients' contribution to the development of a web-based plan for integrated care — a participatory design study.

In this paper we explored the understanding of how service users - adult patients and parents of children with disabilities - could contribute to system development by testing of the SamPro system pilot through a participatory design approach. We focused on the system development from the patient's perspective: testing a web-based tool for ICP based on earlier experiences with health care services and paper-based ICP work, and patient's expectations for a future web-based solution.

The main findings in this study were that patients' contribution to system testing improved the SamPro system and its functionality and usability. Patients and parents contributed through three phases of testing with various areas of focus.

In the first phase, patients and parents contributed with their expectations for this new tool based on their experiences of paper-based plans and former collaboration with the health care service in general. Patients were mainly concerned about system access and system training: "*towards accessing a web-based tool for ICP*". Questions and problems brought forward during system implementation in the real responsibility groups (RGs) as well as during training sessions added valuable information for further system development.

Phase 2 concentrated on how SamPro could *"become a tool for information".* Patients and parents tested available modules, suggested improvements, and new functionality. How this system could ease information retrieval for themselves and the rest of their RG was important to them. They focused on how and where to document information in their e-ICP, and suggested new functionality such as blog sites and “my page”, a front page. They emphasized easy access to and use of the SamPro system according to their own individual needs and wishes, without feeling that they were being pushed to take on tasks or responsibilities they did not want. They did regret that document filing had to be withdrawn from the tool.

In phase 3, patients and parents focused on how this tool could “*become a tool for interaction”* to meet their needs for contact and collaboration with care professionals. Now they tested ways of using the available information in plan meetings and plan evaluation processes. Parents of children with an ICP as well as adult patients expected some functionality in the system to be common to all users, but also wanted functions that could be adapted to their particular situation. This reflected their individual needs and requests for ICP because they had different challenges in collaboration with care professionals. Adult patients emphasized the plan process and experienced that it could empower them to take on planning responsibility themselves, but some felt left alone with little support from care professionals in the planning. Parents showed more interest in the practical possibilities for information storage and exchange in the system available to them in a hectic everyday life.

This paper concludes that patient participation in system testing by the use of participatory design method contributed to system improvements and new functionality in the SamPro system.

7.2.2 Summary of aims and results from paper III:

Title: Web-based collaboration in individual care planning challenges the user and the provider roles. - Towards a power transition in caring relationships.

In this study, we investigated the caring relationship: the patient-professional roles in health care and challenges to the content of these roles due to web-based collaboration in care planning. In this paper, we focused on the use of the web-based tool, although testing activities also influenced the results.

The results showed that both users and care professionals developed a proactive or reluctant role in their e-ICP collaboration, and that meaningful collaboration via the tool failed to become established unless both communication parties had a proactive attitude. Proactive pairs made planning work well: both parties assumed responsibility for care planning and users accessed the tool and interacted actively with their care professionals. The proactive care professionals and the reluctant users worked on the ICP according to a traditional pattern of care, where the professionals are supposed to carry out the care planning and the user is a more passive receiver of the care. We saw a new constellation in this study: proactive users with reluctant care professionals. In these groups, we saw that planning worked because the user had access to the planning system and information stored in it. This constellation also depended on the user's own capacity or willingness to conduct the planning. The fourth possible combination was the reluctant user who had reluctant care professionals in his or her RG. As both parties were passive in planning, we saw no plan activities and a functional and operative ICP never materialized.

Care professionals and patients provided with this new planning tool could test and improvise in daily work with their ICP. Online planning created new possibilities but also additional tasks not seen before: being system superusers (mainly professionals). Information was available to both parties at the same time, and we saw that computer skills could be higher among patients and parents than among care professionals.

This paper showed that use of e-ICP challenged the roles of those involved. We saw a new power relation in care processes: proactivity or reluctance became visible on both sides and some patients saw an opportunity to take more responsibility for their care planning. For some participants this was a new understanding of their role in relation to the traditional patient/provider constellation. A power transition took place from care professionals to patients in the care process leading to patient empowerment.

8 Discussion

The main purpose of this PhD project was to explore in what way a web-based solution for an individual care plan could contribute to achieving the goals in the governmental ICP-strategies. In the following, I discuss results including both ICP and e-ICP in accordance with the theoretical approach of this thesis. The headings reflect this: (e)-ICP.

8.1 Implementation of the (e)-ICP policy

According to governmental estimates at the time that the ICP strategy was being prepared, 3 % of the population would benefit from an ICP, as presented in paper I. The number of potential ICP recipients increased when the ICP law and regulations were extended to cover social care services in 2005, but I found no corresponding update to governmental estimates to address this increase. Paper I showed that the actual proportion was 0.5% in 2005, increasing to 0.58% in 2010 (Rambøll management for Helsedirektoratet, 2011). The Rambøll report shows a marginal increase in the rate of ICP use in health and social care services even after laws required the solution to be offered to a larger group of citizens (Forskrift om individuell plan, 2005). Both Hansen (2007) and Holum (2012) found that lack of organizational supportive models and follow-up have been barriers to ICP dissemination. This may correspond to the result in paper I showing that the low use of ICP was not associated with the type of local political governance, funding or planning activity methods. It is acknowledged in both paper II and III that patients experienced ICP challenges that were also related to organizational concerns, not solely to technological barriers associated with introducing the SamPro system. The governmental strategies to increase ICT communication to support ICP activity have not been adequately implemented in the municipalities: study I showed the use of ICT tools as a word processor for documenting ICPs, but use of telephone or physical meetings as the preferred way of communicating in planning. Neither do any of the four research projects in the field of ICP conducted since 2004 (Holck, 2004, Hansen, 2007, Humerfelt, 2012 or Holum, 2013) include results showing the use of web-based collaboration in ICP activities. This gap between governmental ICP policy and its implementation is also shown in paper II. As described earlier in this thesis, legal restrictions and technological shortcomings as well as organizational challenges made it difficult to realize the full expectations of the test participants.

Implementation of ICP has not succeeded in achieving the intentions of integrated care as presented in figure 2: at the macro level of integrated care, laws and regulations represent the normative side. This side restricts the functional side of integration represented by e.g. the governmental guidelines for ICP. At the meso level of organizational and professional integration, the normative side is represented by ICP commitment for planning, and the functional side by the practical collaboration in individual care planning. Professionals coordinate and integrate caring activities, as shown in the results of this study. At the level of person-based care, we find clinical integration. In the context of ICP, this is not a result of collaboration through fully institutional integration on the normative side, demanding reorganization of care service structures to provide ICP for patients. This is rather a functional cross-clinical integration: a close collaboration without hindrances between care providers involved.

Integrated care theories as presented in figure 1 cover a wide range of care levels. ICP requires at least information sharing and communication at a lower level of integration. It aims to reach the upper level as a care chain where care transformation takes place in order to meet the needs of the patients (Minkman, 2012). In paper II and III we saw this level of integrated care being developed towards what (Minkman et al., 2009) describe as: "Partners in the care chain explore new options for collaboration in the external environment with other partners." With ICP, patients and care professionals tested web-based ways of communication and collaboration. ICP policy documents advocate an active, empowered patient role, but in integrated care theories presented in chapter 3, patient participation is regarded mainly as a role of care service recipients. Konrad (1996) briefly described patient participation, and in Minkman (2012), presented in figure 3 the concept "client centeredness" was used.

Paper II showed the possibility to strengthen this empowered role through patient participation in system development and use. Patients were encouraged to participate actively in system testing as a response to the ICP policy. The lack of harmony between the normative and functional side of integrated care policy might nevertheless result in an unequally distributed service for those in need of an ICP. First, few of the patients who are entitled to a plan have one at all, as shown above. Second, whether municipalities implement an e-ICP or not determines whether these citizens and care professionals will be offered an online collaborative solution. This might lead to disparities in the service provided, as well as inefficient professional collaboration. This was not the governmental intention for ICP. Paper II also showed that the patients and parents had various reasons and goals for their participation in system testing. Many of them contributed not only for their own benefit, but also to improve ICP for other users. They demonstrated mastery in a collective and political position in terms of the patient empowerment theory of Askheim (2012). Table 1 shows the collective and political positions grouped as one, in our case suggesting that ICP policy in a collective position through use of web- based ICP collaboration also could have political impact for groups of patients.

The PPI theory presented in chapter 3.2 supports the e-ICP implementation this way: patients and parents were invited to be active system testers. They participated in 1): development of future services by testing the SamPro system and suggesting improvements and new functionality, and 2): the entire research circle because some acted as co-researchers in Study II. These are two of the five main categories of PPI (Tritter, 2009).

8.2 The care professionals and (e)-ICP

Study I showed that many groups of care professionals were involved in ICP. Initiatives to establish plans and the main workload in planning were nevertheless mainly assigned to or taken on by municipal nurses, social workers or teachers. GPs or hospital staff were less active. Results from Study II confirmed this pattern. One reason may be that patients are encouraged to influence the choice of participants in their RGs, and ask for care professionals they most frequently collaborate with (Thommesen et al., 2003, Humerfelt, 2012). The results in paper III show that the choice of participants in their RGs reflected their respect for the busy schedule of most GPs and psychiatrists. The same concern was not expressed for nurses, social workers or teachers who were involved.

Paper I showed that patients participated in individual care planning, indicating that care professionals were familiar with including patients. It also showed the extent to which they used e.g. meetings, telephone or postal letters to collaborate in planning. Care professionals participating in study II emphasized the structured outline that the e-ICP gave them for the planning process. It improved the organization of ICP activities because care professionals had access to online updates of the ICP activity they were involved in. On the other hand, the e-ICP increased the workload for the coordinators in particular: they had the new super-user task to deal with. The theories of integrated care presented in chapter 3.1 focus more on the process and levels of integration than on distribution of tasks among involved groups of care providers, e.g. whether some groups of care professionals should be preferred to others for caring contact with patients (Konrad, 1996, Leutz, 1999, Ahgren, 2012, Minkman, 2012). Among these theories, some involve health care professionals as the only group providing care integration while others also include professions outside the traditional care service system (Coddington et al., 1994., Leutz, 1999). Patient empowerment theory supports the principle that patients want to choose how and from whom to receive care (Freire, 1970, Victoor et al., 2012). This understanding of patient empowerment might be placed in the individual market-oriented position of patient empowerment shown in table 1: patients made their choices for health care service based on their personal needs and preferences (Askheim, 2012). If the reason for choosing some groups of care professionals is respect for the busy schedule of other groups, this might indicate that these busy groups do not meet the patient's needs for care planning. To vote out those who do not meet your needs is also a case of empowerment. If the choice of RG members is based on reluctance to bother busy professionals, this could be a humble patient role, not influenced by PE. Neither is this role understanding consistent with the theory of new public management (NPM) and PPI introduced in chapter 3.2. Together with PE they call for patient and citizen influence and self-determination in contact with health care services (Aujoulat et al., 2007, Djupvik and Eikås, 2010b, Mockford et al., 2012). This is not met from care professionals in the example above.

Results in paper II and III showed that care professionals expressed little concern about sharing plan documentation or even the responsibility for developing the plan with the patients or parents – a task that had previously been restricted to the professional domain. This care plan transparency and role transition might be seen as elements increasing PE and

PPI in care planning. They reflect both the collective position in the counter-power position and the individual level through the market-oriented position of PE in table 1. Both the collective and the individual positions of patient empowerment are targets of care services in the described ICP and ICT strategies.

All five categories of PPI presented in chapter 3.2 could be relevant to discuss related to the care professionals and the e-ICP system testing. Here I focus on one of them: education and training of care professionals. Some patients were more skilled in computing and trained their care professionals in computing, while others brought new ideas to the testing as shown in paper II and III. In this way, patients and parents provided new knowledge to the care professionals involved. On the other hand, reluctant or non-participating care professionals might have weakened the impact of the ICP tool for the involved patients. This reluctance is described in paper III as an organizational hindrance: it is also regarded as personal because of lack of ICT competence or practice. Figure 1 shows that levels of integrated care also might cover the level of no integration, the so-called antagonist level. This reflects the attitude of reluctant care professionals in an e-ICP setting. Those who performed their ICP tasks at this “antagonist level” or a low level of “information sharing” performed their tasks in conflict to the policy of ICP and plans for e-ICP (Individuell plan, 2010). Organizational or personal reasons for reluctance among care professionals shown in paper III should be addressed in further development of integrated care theory to secure equitable distribution of care.

Paper II demonstrated that the participants had expectations of improved and flexible communication through a web-based solution. The ICP has also been promoted as an improvement for patient/provider communication in terms of both efficiency and quality of care (Individuell plan, 2010). The secure health network as the only accepted internet communication for health care issues restricts needed and requested integration of care as long as groups of caregivers and patients themselves are not permitted to access e-ICPs through this network. Restrictions in existing laws resulted in disparities in online communication, as experienced in study II. The legislation does not restrict citizens from posting questions or remarks concerning their own health care conditions to a care professional. The legal provisions apply to care professionals, who until the new law was ratified in January 2015 not could respond online without violating the Personal Health Data Filing Act (Helseregisterloven, 2001, Helseregisterloven, 2014). Results from study II show that neither care providers nor patients were concerned about any security breaches in web-based communication. This shows a divergence: citizens and care professionals request and trust web-based communications for functional integration of care while decision- making politicians and government executives, the normative side of the integrated care domain presented in figure 2, develop the requested solutions at a slower pace than requested (Valentijn et al., 2013).

Because ICP involves the patient, sometimes the next of kin, and a varying number and range of care professionals, there is a demand for flexible solutions and tools supported by laws, regulations and organizational structures. Both study I and study II indicate that care professionals so far have been in charge of or participating in planning without appropriate ICT and organizational tools to meet the demand for care planning results.

8.3 The patients and (e)-ICP

Both study I and study II showed that patients participated in care planning when a plan had to be or had been established, and paper II showed that they contributed substantially in e-ICP system development. Even so, the number of ICPs in paper I proved low, and patients rarely initiated ICPs themselves. In paper III we found that some patients also had a reluctant role regarding the SamPro testing. Paper I does not explain the low number of ICPs or the low level of patient initiative, given patients' right to an ICP. One reason may be that ICP was still little known and not widely promoted to the public at the time of data collection (Andersson et al., 2005).

Results from paper II and III showed that patients and parents had varying experiences with health care services when they joined the system testing in Study II. This led to varying expectations for the system to solve their requests. This non-homogenous group of patients and parents contributed to system development because they were enabled to participate through a PAR and PD design.

Paper II and III showed variety in planning participation, either depending on, or acting more independently of their RGs. This reflects an empowered stage according to the ICP intention: during testing we found that patients took more responsibility than expected from ICP policy documents because they had the possibility of accessing their own ICP, e.g. by wanting to be their own coordinators as shown in paper III (Heldal and Tjora, 2009). Responsibility was also extended when care professionals showed reluctance in e-ICP activities, not taking on their ICP duties, also shown in paper III.

The development and system testing of SamPro could be seen as both individual and collective/political positions in terms of the patient empowerment theory presented by Askheim (2012). Paper II showed that patients initiated system development according to their own needs through testing of the SamPro system. They also influenced their own patient role as shown in paper III. This demonstrates a counter-power position with the possibility of improving mastery of one's individual life conditions through online care planning. The table also presents three positions of individual patient empowerment, all of which applied to patients and parents. *The first individual position* is the market-oriented position, typically a position for the parents of child patients who in paper II showed that they emphasized SamPro as an organizing tool in daily life. This is also an answer to the NPM ideas, where patients require care services, and care professionals respond to their requests (Djupvik and Eikås, 2010a). Results from both paper II and III showed that adult patients also took on *the second individual position*: a self-therapeutic position, as they had ICP access through the SamPro tool and governed care planning as independently as they wanted. The development of the blog functionality shown in paper II underpins this position. When patients entered the role as their own plan coordinator, this could be seen both as a self-therapeutic position and as *the third individual position*: a self-realization position. The third position was also expressed through better control over life planning process, and increased quality of life as shown in paper II.

The possibility of empowerment through use of the SamPro system in study II depended on system availability and the capacity of parents and patients for using the tool for communication and planning. Results from paper II showed that parents reported having little time to spend on extra duties such as online activities. Some adult patients had no computer, while other patients as well as parents experienced limitations such as internet line capacity. We did not find PC user barriers other than lack of computer availability or line access among our patients and parents, but lack of technical or digital skills or cognitive barriers to the use of a computer can also be limitations influencing e-ICP activity. As discussed above, reluctant care professionals in combination with lack of planning capacity among patients or parents could restrict empowerment (Coulter, 2010) . Possible restrictions should be addressed to secure an equitable care service and patient empowerment. On the other hand, to be proactive or reluctant in care planning based on the patient’s own choice, as shown in paper III, reflects patient empowerment. Here, patients participated according to their own wishes and capacity, but were spared the responsibility for planning by care professionals who took on their professional ICP duties as implied by ICP policy expectations. The main focus in integrated care theory is the interaction between various groups of care professionals and how they collaborate. An adjustment should be considered to give patients a possibility to become proactive partners by including elements from the theory of patient empowerment into the integrated care theory domain.

8.4 Methodological discussion

This thesis relies on multiple methods to answer the research question.

We considered telephone interviews for data collection in study l. A postal mail questionnaire was chosen because some of the questions required specific knowledge or numbers that we not could expect to receive as direct answers in a phone call (Polit and Beck, 2012). Reminders were provided by phone, which increased the response rate (Dillman et al., 2009). We found no way of asking patients or parents of child patients with ICP about their opinions and experiences in study 1. Because we asked municipal leaders and not patients and parents in the study, we received no answer about whether the remaining proportion of the citizens entitled to an ICP had considered, but not initiated a plan themselves, rejected an ICP offer from their care providers, or not been offered a plan.

More research is needed to provide information about how care professionals meet new patients or parents who ask for an ICP and how the public now receive information about ICP.

In study II, it was harder to get participating RGs established and trained than anticipated. This challenge was partly based on the fact that several care providers in the participating municipalities had little experience in ICP establishment before the SamPro testing started.

The divergent experiences, expectations, and role understanding in the heterogeneous group of participants in study II required an open-minded approach to testing. Unforeseen situations as described in the SamPro project presentation in chapter 4.1 resulted in an unpredictable testing process: legal, organizational and technical challenges merged and influenced system testing. This flexible way of accomplishing the system testing project influenced the action research project: the research could not be stringently planned e.g. in accordance with a time scedule. A method other than PD might not have captured the testing participants' information the way PD did in our study. By use of both PAR and PD as methods, we invited a close interaction between system testing and research. This could have become a source of bias if not acknowledged.

In addition to being both project manager and researcher in Study II, I was aware of the influence of my professional background as a trained nurse. Participating patients, parents and care professionals were all informed of my roles and nurse profession. I had the advantage of bringing theory from my profession into the research. Travelbee (1971), Eriksson (1987), and Martinsen (1990) all focus on patient-centred care and patient empowerment through practical and moral aspects of the relationship between patients and nurses. My experience as a nurse could have caused bias if I had entered a therapeutic role of nursing. As a precaution, I was not in the front line assisting in daily testing and problem solving, and the RGs took care of the patients' and the parents' needs of care. My independent PhD role was highlighted in contact with testing participants. Another precaution was to establish contact with external scientific groups for discussing ICP and methodological topics. Instead, many years of clinical and leading nursing experience as well as ICT project management positions provided insight into the complexity of collaboration in individual care planning. This was valuable in gaining understanding of the informants and the collected data in the analysing process. By taking precautions as described, I regarded my roles as being a nurse, a researcher and a testing project manager in total as an advantage more than a potential problem in the context of the research project.

9 Concluding remarks:

The main contribution of this thesis is the demonstration of the challenge of implementing (e)ICP as a tool for integrated care in healthcare services in Norway:

- E-ICP challenged the concept of integrated care because participating patients have the opportunity to become more active in planning themselves by care plan access. This progress calls for patients as active partners, not passive care recipients in future integrated care models.
- Patients and parents of child patients could gain control of their lives and attain an empowered role through the use of the e-ICP solution. The thesis shows that these groups of health care service recipients took the choice of being either active or passive partners in care planning. On the other hand: the digital divide among testing participants restricted collaboration in e-ICP testing. This could cause less patient empowerment.
- The use of an action research approach and the method of participatory design proved to be a sustainable method to study user participation in an unpredictable testing situation. This thesis shows a way of future end–user participation in system development.

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Research and Theory

Integrated care in Norway: the state of affairs years after regulation by law

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Abstract

Introduction: A mandatory multidisciplinary plan for individual care, the 'Individual care Plan', was introduced by law in Norway in 2001. The regulation was established to meet the need for improved efficiency and quality of health and social services, and to increase patient involvement. The plan was intended for patients with long-term and complex needs for coordinated care. The aim of this study was to elaborate on knowledge of such planning processes in Norwegian municipalities.

Method: A piloted questionnaire was sent to 92 randomly selected municipalities in 2005–2006, addressing local organization and participation in the work with individual care plans. Local political governance, size of the population, funds available for health care, and problems related to living conditions were indicators for analysing the extent to which the individual care plan was used five years after the regulation was introduced.

Results: Our results showed that 0.5% as opposed to an expected 3% of the population had an individual care plan. This was independent of the political, social and financial situation in the municipalities or the way the planning process had been carried out. The planning process was mostly taken care of by local health and social care professionals, rather than by hospital staff and general practitioners.

Discussion and conclusion: The low number of care plans and the oblique responsibility among professionals for planning showed that the objectives of the national initiative had not been achieved. More research is needed to determine the reasons for this lack of success and to contribute to solutions for improved multidisciplinary cooperation.

Keywords

health policy, health planning, patient care management, primary health care, patient centred care, individual care plan

Introduction

According to both scientific and government publications, a growing number of people need better coordination of care across health and social services that involve a number of carers [1–5]. International research shows that coordinating models have been initiated and established mainly at local levels and as projects more often than as permanent services [6]. The Norwegian government decided to try another approach. The 'Individual care Plan' was introduced by law in 2001 at national level, giving patients the right to receive managed and coordinated care and to be involved in the process of shaping their own services [7].

Since the law was passed, all kinds of patients in need of wide-ranging health and social services over time have had a legal right to an individual care plan including a named person to coordinate the services. It has been estimated that about 30 per 10,000 people or 3% of the population might benefit from such a plan. The numbers are based on statistics for illness and disability in Norway [3]. An individual care plan includes an outline of the patient's objectives and resources as well as the services required, independent of diagnosis or age or level of care. Typical patients covered by the legislation include people with a severe psychiatric diagnosis, disability, or drug addiction, as well as elderly patients with comorbid conditions who need coordinated care across organizational boundaries. The planning process is to be started as soon as requested by any party, including the patient, next of kin or legal guardian. The health or social provider is expected to offer an individual plan as a natural part of treatment. This plan is not a substitute for the patient record and does not contain detailed social or health personal data. The areas mapped are mainly needs and resources in health, finances, housing, and social life as well as kindergarten, education or work. The main function is administrative: to define goals and tasks for selected areas, specify the responsible providers and indicate a schedule or timetable. The collaborative process is essential and even professionals outside health and social care, mainly teachers, can initiate and participate in the care planning process. Teachers typically contact the health visitor or social welfare officer to start the collaborative planning process. They can mutually benefit in their work in relation to, for instance, a disabled child by cooperating across organizational boundaries.

The Norwegian Directorate of Health has prepared guidelines, held courses, and initiated projects to inform professionals and managers about individual care plans and to ensure that both hospitals and municipalities achieve proper planning processes. Although great efforts have been made to stimulate the use of individual care plans, a national survey has indicated that interest in using individual care plans has been low or modest [8].

The purpose of this study was to explore the use of individual care plans in Norwegian municipalities that are responsible for primary care and social services:

1. How extensive is the use of individual care plans?
2. Is deployment of the plans influenced by the municipality's size, local political dominance, or financial situation, or by indicators of living conditions in the municipality?
3. How do municipalities initiate and organize the process of implementing individual care plans?

Norwegian municipalities are run by local councils. Most of their health and social care duties are regulated by law and are financed by general grants or national earmarked grants. However, there are variations due to local political government, prioritizing of available resources, and differing needs [9,10]. There are also variations in living conditions [11].

Methods

Selection of participants

A sample of all 420 municipalities was selected in two steps following the approach suggested by Groves et al. [12]. First, the municipalities were proportionally stratified into three groups according to size following the classification provided by Statistics Norway (SSB): small (<5000 inhabitants), medium-sized (5000–19,999 inhabitants) and large (≥20,000 inhabitants) [13]. From each group, 20% was randomly chosen by throwing a dice, i.e., 46 small, 30 medium-sized and 16 large municipalities. The largest municipalities were represented by drawing one or two internal districts according to their size.

Questionnaire

We did not identify any validated questionnaire suitable for our purpose and had to develop one from scratch. National and international literature and theory describing coordinated and multidisciplinary care as well as our own experience with individual care plans were used as the background [5, 14–16]. The first section in the questionnaire covered information about characteristics of the municipalities, such as size and deployment of individual care plans. The second section comprised questions about who initiated an individual care plan, who managed the plan, and who participated throughout the planning process, including patients and next of kin. We used a combination of yes/no questions and 5-point Likert scales where 1='always' and 5='never'. The questionnaire was piloted by asking 11 nurses, social workers and patients who were familiar with the concept of individual care plans to go through it [17]. They were then interviewed about their opinion of both the questions and the layout of the questionnaire. A few minor changes were made as a result.

Data collection and analyses

The questionnaires were distributed by post in November 2005. Two reminders were sent, and the last response was received in July 2006. As there are minor organizational variations nationwide, we decided to simply ask the municipality administration to identify the person who had the best local overview of, or knowledge about use of individual care plans and hand over the questionnaire to this person.

The municipality reference number was used to link the questionnaire with additional demographic information about each municipality from the public information source in [9–12]. An index was used for living condition problems, based on the sub-indices social assistance, mortality, disabled pensioners, rehabilitation assistance, violence, unemployment, transitional benefits and proportion with schooling limited to compulsory education [10]. Data were analysed using SPSS version 16.0. Frequencies were used to describe the distribution and organizational aspects of the care plan processes. One-way analysis of variance (ANOVA) tests were carried out to analyse structural correlations between characteristics of the municipalities and distribution of individual care plans. One-way ANOVA tests were also conducted to analyse coherence between distribution of individual plans and organizational factors.

Ethical considerations

The survey was approved by both the Norwegian Social Science Data Services (NSD) and the Regional Committee of Medical Research Ethics (REK).

Results

In total, 61 (66%) municipalities responded out of the 92 municipalities to which the questionnaire was sent (small municipalities 31/46 (66%), medium-sized 21/30 (70%) and large municipalities 9/16 (56%). Thirty-two (53%) leaders in health or social care and 27 professionals (44%) answered the questionnaires. Altogether 50 (82%) municipalities stated the number of patients with an individual care plan in their municipality, including 23 (38%) which gave an approximate number of plans. Thirty (49%) municipalities knew the exact number of plans. Municipalities that gave the exact or approximate numbers of plans are treated alike in analysing prevalence of plans. All municipalities were included in analysing organizational matters.

Individual care plans in relation to municipality characteristics

In the municipalities that had stated their number of individual plans, the average number of people with individual care plans was 50/10,000 inhabitants (range 40–150 of 10,000) consequently, of the eligible patient group expected by health authorities, just under 1700/10,000 (17%) had a plan.

Table 1 shows that the size of the municipality had no significant influence on its relative number of plans. Neither did we find any significant relation between the number of individual care plans and municipal health and social care funding, political governance or the municipal index for living condition problems.

Management of individual care plans in the municipalities

The planning process was divided into three phases: initiation of plan, appointment of individual care plan manager, and the collaborative planning process.

Table 1. Prevalence of individual care plans in relation to municipality characteristics

	Public indicator values	Number of individual care plans per 10,000 inhabitants	One-way ANOVA
Size of municipalities	Small <5000	62 (n=24)	$F_{(2.47)}$=2.034, p=0.142 n=50
	Medium-sized 5000–19,999	39 (n=18)	
	Large ≥20,000	49 (n=8)	
Free available municipal funding per inhabitant in health and social care	Low funding <10.00 NOK	45 (n=5)	$F_{(2.46)}$=0.284, p=0.754 n=49
	Medium funding 10.00–19.99 NOK	53 (n=42)	
	High funding ≥20.00 NOK	34 (n=2)	
Political governance	‘Red’ wing parties	55 (n=32)	$F_{(1.48)}$=0.570, p=0.454 n=50
	‘Blue’ wing parties	46 (n=18)	
Index of living conditions problems	Upper half 1.0–5.0	47 (n=26)	$F_{(1.48)}$=0.986, p=0.326 n=50
	Lower half 5.1–10	57 (n=24)	

Table 2. Extent of initiation, management and participation in collaborative planning of individual care plans among patients, health personnel and others in municipalities (n=61)

Participants	Initiation of individual care plans				Management of individual care plans				Participation in individual care plan collaboration			
	Often	Occasionally	Seldom	Missing/ no answer	Often	Occasionally	Seldom	Missing/ no answer	Often	Occasionally	Seldom	Missing/ no answer
Patients/next of kin[1]	10 (16%)	24 (39%)	20 (33%)	7 (12%)	1 (2%)	2 (3%)	44 (72%)	14 (23%)	–	–	–	–
Local nurses[2]	36 (59%)	21 (34%)	1 (2%)	3 (5%)	29 (48%)	23 (38%)	2 (3%)	7 (11%)	33 (54%)	23 (38%)	1 (2%)	4 (6%)
Social workers	21 (34%)	25 (41%)	10 (17%)	5 (8%)	22 (36%)	15 (25%)	15 (25%)	9 (14%)	35 (57%)	17 (28%)	6 (10%)	3 (5%)
Teachers	11 (18%)	19 (31%)	18 (30%)	13 (21%)	7 (11%)	9 (15%)	32 (53%)	13 (21%)	28 (46%)	25 (41%)	4 (7%)	4 (7%)
GPs	0 (0%)	15 (25%)	33 (54%)	13 (21%)	0 (0%)	2 (3%)	44 (72%)	15 (25%)	16 (26%)	22 (36%)	17 (28%)	6 (10%)
Hospital staff[3]	9 (15%)	29 (47%)	15 (25%)	8 (13%)	0 (0%)	8 (13%)	37 (61%)	16 (26%)	19 (31%)	34 (56%)	5 (8%)	3 (5%)

[1] The municipalities were not asked whether patients participated.

[2] In the first column, initiation of IP, physiotherapists and health visitors were also included together with nurses.

[3] Hospital staff includes both hospital wards and out patient clinics.

Table 2 shows that nurses initiated and managed individual care plans most often, compared with others. Social workers, nurses, and teachers participated most frequently in the collaboration. Patients or next of kin did not often initiate plans themselves. Hospital staff and general practitioners (GPs) participated overall to a low extent. We found a relationship between levels of initiation and management in the groups of nurses, social workers and general practitioners. Analysing municipal distribution of plans with variables in Table 2 showed no significant correlation.

Collaboration and documentation methods

We asked for collaborative and documentation routines in order to map organizational aspects relating to the development of individual care plans.

Table 3 shows that drawing up an individual care plan is usually a collaborative process. Meetings were the most common form of collaboration, followed by telephone conversations. Our survey showed that nearly all the professionals participating in planning processes had access to ICT tools, but specific templates or applications for plans were seldom used in the documentation. A word processor seemed to be the preferred tool. Even handwriting was still fairly extensively used. Analysing coherence between prevalence of individual plans in the municipalities and planning activity methods yielded no significant results.

Discussion

This survey shows that the deployment of individual care plans is still far from covering the expected needs, five years after they became a legal right and after other initiatives launched by health authorities. Municipality authorities are responsible for the implementation of individual care plans, but local demographics or organization of planning processes do not seem to influence the deployment.

Study limitations

Professionals in different positions answered the questionnaire, because local authorities were able to choose the respondent on behalf of the municipality. Many municipalities did not have a complete overview of the local work done in relation to individual care plans and could not answer some of the questions. This may have introduced a bias of which we are unaware.

A larger sample might have improved the statistical reliability in general. The sample size covering a fifth of the population was considered sufficient for analy-

Table 3. Distribution of collaboration activity and documentation tools in working with individual care plans in municipalities (n=61)

	Always/often	Occasionally	Seldom/never	Missing/no answer
Collaboration				
Meetings	51 (83%)	6 (10%)	0 (0%)	4 (7%)
Only one author	8 (13%)	7 (12%)	41 (67%)	5 (8%)
Telephone	9 (15%)	18 (30%)	29 (47%)	5 (8%)
Mail correspondence	8 (13%)	8 (13%)	39 (64%)	6 (10%)
E-mail correspondence	2 (3%)	6 (10%)	47 (77%)	6 (10%)
Documentation				
Electronic patient record	8 (13%)	3 (5%)	40 (66%)	10 (16%)
Specialized ICT tool for IP	16 (26%)	4 (7%)	29 (47%)	12 (20%)
Word processor	37 (61%)	8 (13%)	5 (8%)	11 (18%)
Handwritten plans	14 (23%)	8 (13%)	29 (48%)	10 (16%)

sis due to the stratification and overall homogenous, nationally regulated structures in Norwegian municipalities. We did not find any demographic or geographic differences between respondent and non-respondent municipalities. We do not believe that the non-respondents would have caused results favourable to the deployment or use of individual care plans [18]. In all, we do not expect that an increase in the population size would have influenced our conclusion.

Another weakness is that all the information we have obtained about patients' experience and involvement in the use of individual care plans comes from answers given by the service providers.

Deployment of individual care plans

Individual care plans have been regarded as an aspect of integrated care internationally [19]. We believe that Norway's systematic national approach to care planning is unique in being mandatory for all service providers on an equal basis. It assumes and requires multilevel and multidisciplinary collaboration that is broader and includes more services than has been customary in many instances [6, 20]. According to political statements in Norway, the use of individual care plans is an important indicator of quality of care and user satisfaction [21].

However, our study provides no explanation for the low number of plans and the lack of overview of their number of plans. This may indicate modest interest or local barriers to individual care plans as a model of care. Small municipalities have generally invested more in health care services than large ones, and municipalities with a high degree of funding at their disposal for health and social care have spent more money on elder care than other municipalities [22, 23]. We did not find that this pattern applied to individual care plans. Political views and financial allocations are important at national level, but—as demonstrated here and by others—the differences between political wings fade away locally [24].

Municipal organization of the work with individual care plans

National health authorities manage specialist care in Norway, but the municipalities have considerable autonomy in their organization and implementation of social and primary care. To achieve well-organized individual care plans of high quality, the need for suitable structures for collaboration and understanding of roles as well as for patient empowerment is emphasized [25–27]. Few patients had claimed an individual care plan on their own initiative in spite of intensive information campaigns and their statutory right to such a plan. One reason might be uncertainty among patients about the benefits [28]. Another reason may be that information was not perceived as expected [29]. Patients who have an adequate individual care plan, however, report that it has contributed to better quality of life [30].

The association between initiation and management of individual care plans we found may indicate that initiating professionals end up managing the plan. Such mechanisms can easily lead to a skewed workload among staff, and might thus have become a barrier to further deployment of plans. Our survey revealed that in the complex coordination of the plans, some professions (e.g., nurses and teachers) were more committed to the planning process than others. This did not follow the traditional hierarchy of patient treatment presented in literature on professions, but showed other layers of responsibility as this management work may have a lower status than other clinical decisions and treatment [31–33].

The low participation of general practitioners in work with individual care plans does not harmonize with the situation of chronically ill patients who depend on and expect involvement from their general practitioners in rehabilitation [34]. Reasons suggested include work patterns socialized in medical education as well as workload [35, 36]. Instead, general practitioners leave multidisciplinary collaborative work to other personnel in the municipality. Hospitals expect municipalities to work out individual care plans, although hospitals have the same independent obligations [37].

The analysis did not explain why teachers initiated plans and participated in the way they did, as they are not formally included in the scope of the law on individual care plans. There is a close working relationship between schools, health visitors and the social care system in Norwegian municipalities, as well as between general practitioners and hospitals, so there must be other reasons. One could be that all disabled children in Norway are integrated into ordinary schools, and rehabilitation of children was one of the areas given priority in connection with the concept of the individual care plan.

Our study supports the view that the organization of the work with individual care plan has been more or less arbitrary. A previous study showed that municipalities and hospitals had not established organizational structures to support individual care plans. This study also shows that there was no connection between measures proposed in individual care plans and health services being provided [37].

Our results may indicate a lack of suitable ICT tools to support the work with individual care plans, as we know from a recent study that 60% of the nursing care services in the municipalities had access to electronic patient record systems including templates for individual care plans [38]. Our study shows that these templates in the EPR were not widely used.

We believe that health and social care services in other countries may learn from Norwegian experience indicating that the implementation success of integrated care processes cannot easily be explored. Legislation, supervision and training programmes have not increased deployment of individual care planning or collaboration processes to an acceptable level. The somewhat skewed distribution of participants being involved across legislation demands should be taken into consideration in plans for similar solutions for integrated care. Although the law assigns equal responsibility for the planning process, our analyses revealed a different reality. The involvement of teachers shows that planning process strategies may benefit from being open even to participants outside health and social care.

Conclusion

Our study supports earlier research indicating that establishing sustainable integrated collaborative care is complicated. Despite legal obligations and national initiatives by the authorities, multidisciplinary teamwork across organizational boundaries in health and social care is challenging. There may be reasons below supervisory economic and political levels that should be explored.

Authors' contribution

Jorunn Bjerkan has been in charge of the data collection and writing process as part of her PhD project. Marie Richter participated in developing and carrying out the questionnaire process, as well as in capturing and analysing the statistical material. Ragnhild Hellesø, Anders Grimsmo and Jytte Brender provided ongoing critical appraisal and contribution of the approach, writing process and interpretation of the results. All authors have accepted the final version of the article.

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Paper II

Paper III

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ORIGINAL RESEARCH

Web-based collaboration in individual care planning challenges the user and the provider roles – toward a power transition in caring relationships

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Background and objective: The Individual Care Plan (ICP) was introduced in Norway to meet new statutory requirements for user participation in health care planning, incorporating multidisciplinary and cross-sector collaboration. A web-based solution (electronic ICP [e-ICP]) was used to support the planning and documentation. The aim of this study was to investigate how web-based collaboration challenged user and professional roles.

Methods: Data were obtained from 15 semistructured interviews with users and eight with care professionals, and from two focus-group interviews with eight care professionals in total. The data were analyzed using systematic text condensation in a stepwise analysis model.

Results: Users and care professionals took either a proactive or a reluctant role in e-ICP collaboration. Where both user and care professionals were proactive, the pairing helped to ensure that the planning worked well; so did pairings of proactive care professionals and reluctant users. Proactive users paired with reluctant care professionals also made care planning work, thanks to the availability of information and the users' own capacity or willingness to conduct the planning. Where both parties were reluctant, no planning activities occurred.

Conclusion: Use of the e-ICP challenged the user–professional relationship. In some cases, a power transition took place in the care process, which led to patient empowerment. This knowledge might be used to develop a new understanding of how role function can be challenged when users and care professionals have equal access to health care documentation and planning tools.

Keywords: integrated care, patient participation, empowerment, role transition, system testing, web-based collaboration, Norway

Introduction

This study explores the ways in which traditional roles of health service users and care professionals were challenged by web-based collaboration in individual care planning. We used data from a larger research project on a web-based tool for care planning called "SamPro", conducted by the hospital trust in central Norway.

The "individual care plan" (ICP) as a concept has been established in several countries, where multidisciplinary and cross-organizational care planning are recognized in concepts such as "patient-centered care", "shared care", "coordinated care", and "integrated care".[1–4] In Norway, initiatives were taken in the late 1990s to address the acknowledged lack of coordinated care, in response to demands from the public and from politicians for improved care and better coordination of the care provided. National and international political trends supported these demands. A requirement to promote ICPs was incorporated into the Norwegian health care legislation and

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in the Patient Rights Act in 2001.[5] ICPs were included in the Act related to social services in 2005.[6] The intention of specifying this requirement in the legislation was to ensure a structured way of planning to encourage user-centered care and thereby to improve the quality of care. Previously, care planning had been accomplished through ordinary patient records, discharge letters, and informal meetings or phone contacts. The scope of an ICP may include different aspects of the user's daily life at a summary level, and therefore takes account a variety of user needs. This new model of cooperation is intended to foster changes in the roles between care professionals and users of the health services, with greater participation by users in care planning and management. No default template was required for the plan apart from the main principles for ICPs specified in Norway's health and social care legislation (Table 1).

The ICP is an overarching plan: a tool supplementing each professional's plans, which does not replace the patient records, but is intended to strengthen the coordination between care professionals and the patient.

A web-based system for ICP: SamPro

The electronic ICP (e-ICP) is a web-based tool where participants access the ICP document and planning process via the Internet using encrypted log-on procedures on their own mobile device. This means that users and care professionals can interact or collaborate electronically across organizational boundaries or locations. The e-ICP is a supplementary and structured tool based on the individual patient's needs, supporting responsibility group (RG) meetings and everyday human interaction in care planning.

Table 1 Principles of ICPs as stated in Norwegian legislation

Users who need long-term and coordinated care are entitled to a care plan. There is to be only a single ICP per user.
User consent is mandatory for establishing an ICP.
User participation in planning is emphasized.
A named plan coordinator is appointed for each individual plan. This task may be covered by any one of a variety of care professionals – often nurses employed by municipal health services.[7]
RGs are often established, but they are not mandatory. An RG may comprise the coordinator, the user, and a number of named care professionals, and sometimes the user's family members.
Life areas covered by the ICP include health care, work or education, finance and housing, social life, and other life situations, depending on each user's needs.
An ICP identifies key goals and the resources, objectives, and tasks necessary for meeting different aspects of the user's needs. The plan indicates the distribution of responsibility between the user and the different professionals, and a timetable for action.[7,8]
The plan document is available to external care professionals only if the user's approval has been obtained.
The municipalities have a statutory responsibility to review each ICP at least annually. They report regularly on the number of service users who have been offered an ICP, and who have accepted it.[9]

Abbreviations: ICP, individual care plan; RGs, responsibility groups.

The e-ICP system described in this article, "SamPro", was developed through a joint venture project between the hospital trust in mid-Norway and the system vendor Visma to meet the statutory requirements by enabling efficient care planning and management. The hospital trust wanted a system for its region; the vendor was interested in future expansion in other parts of the country. This project aimed to provide access to care plan information across units at both municipal and hospital care levels. The aim was to enable users to participate in this online documentation and communication on equal terms with care professionals. The system was web-based with no need for installation of software or hardware on users' PCs. This system was developed for future use in other parts of the country after being developed and tested in mid-Norway municipalities and hospitals. Additional web-based functionality beyond the statutory requirements included activity logs, SMS, and an internal email module.[10] The SMS functionality was used for log-on procedures and for alerts of participant log-on for plan updates. The Document module included the required needs assessment goals and actions as well as a timeline for plan actions and evaluation of each action. The use of computer-based support for preference-based care planning is increasing. Research shows that such support can improve user-centered care and patient outcomes,[11,12] and might also contribute to power transition in health care relationships.

Transition of power in new health care relationships

In recent decades, the paternalistic role of user and care professionals has been challenged. For instance, both new public management in public services and movements to promote the rights of users, such as patient and public involvement, have questioned the ways in which care and treatment is provided for people with disabilities or health care needs.[13,14] Freire introduced the concept of "empowerment", aimed at policy movements for citizen rights and freedom of the individual.[15] In the 1980s, Rappaport developed an individual psychological concept for community psychology stating, "Empowerment is the mechanism by which people, communities and organizations gain mastery over their lives."[16] Associated with user involvement, empowerment involves participating in processes of sharing something in common with others and in activities that increase people's ability to make choices for themselves, which implies consciousness-raising and capacity building.[17,18] Users' movement out of an unbalanced relationship can be seen as an individual power transition. However, embracing empowerment means making a paradigm shift which is often difficult because the traditional approach to care is embedded in the training and socialization of most health care professionals.[19] Research also confirms that the level of user involvement or sharing of real power with the users in care planning is still low. Care professionals experience difficulty in establishing cooperation with users or in adopting the idea of real power transition.[20,21] In this study, we focus on the philosophy of ICPs and specifically on the roles of users and of care professionals, described in the Norwegian White Paper "From Patient to Citizen".[22] For health care providers, the implementation of ICPs is a journey from a paternalistic professional role in a hierarchical organization model toward a new asymmetric and multi- or even trans-organizational model of care.[23,24] The consequences of such a shift will probably influence transitions toward more balanced power in the collaboration and decision process between users and professionals, but success seems to be influenced by various prerequisites.

Meleis defines transition as a passage or movement from one condition or state to another, which can lead to the development of new models and organizational systems, as well as to health–illness transition.[24] Since implementation of ICPs requires both a new level of planning and changes in user–professional relationships, it is an example of both organizational transition and health–illness transition. It may include new patterns of behavior and mastering of new web-based technology, by both users and care professionals. With reference to international research, Schumacher and Meleis suggested that one indicator of successful transition is the achievement of skilled performance, competence, and the new behavior required in the new situation. In addition, a feeling of well-being with the interpersonal relationship, here between care professionals and users, is important. Success is also dependent on a realistic expectation of the outcome from those involved. The quality and effectiveness of the planning that occurs before and during the testing and implementation of a new model, such as an e-ICP system, are conditions that can influence the success of a power transition. Several studies refer to stress and emotional distress, linked with relational conflicts, feelings of insecurity, being overwhelmed, and defeated. Negative feelings may result in unwillingness to take the risks or in actual avoidance of participation.[25]

Transition theory highlights the importance of understanding transition from the perspective of those involved in the process. However, research dealing with the concept of role transition focuses mainly on the health care professionals' roles, with patients or users mentioned as the recipients of the improved quality of care.[26–28] Few research projects discuss transition as it affects both users and professionals in a common context. Two studies of the interactions of patients and pharmacists[29,30] conclude that there is a need for improved congruence between the parties, which is a focus of this study.

Primary objective

The primary objective of this study was to investigate the user–professional roles in health care and the ways in which these roles are challenged through electronic collaboration in care planning. The research question was: "In what way was the role of care professionals and users challenged during implementation of web-based collaboration in individual care plans?"

Research design

This is a qualitative study using data obtained during the SamPro implementation project. The study lasted from May 2005 to July 2007. Participants in RGs – users and care professionals who had actively participated in the testing of the web-based system in the "SamPro" project – were asked to take part in interviews. Both individual interviews and focus-group interviews were conducted; we chose what was possible to carry through and what would give most value to this study. We arranged focus-group interviews among coordinators of RGs at one test site because they had regular meetings discussing testing experiences and challenges. They had established an open dialog which we wanted to include in our study because we believed this would enrich the result. In the mental health context, it was not appropriate to organize focus-group interviews. For parents, time was restricted, and we could not expect them to prioritize such a group meeting. For example, we had to go to one family home in order to conduct the interview because this was the only possibility to arrange a meeting.

Methods

Setting and participants

The setting for the study consisted of five municipalities in the Central Norway region chosen by the regional hospital trust. Participants were drawn from three pilot sites and their affiliated hospitals.

The main inclusion criterion for users was entitlement to an ICP.[6] All adult users and the majority of child users had more than 2 years' experience of ICP paper-based plans. In this study, the term "users" refers both to adult service users aged 18 or more and to parents of children with disabilities who were part of the study. Adult users had severe psychiatric diagnoses, while child users had various disabilities, which entitled them to coordinated care. When it is appropriate to distinguish between these two groups of users, they are referred to as "parents" and "adult users". The main inclusion criterion for care professionals was their participation in RGs established for the support of the users included in the study. A common inclusion criterion was access to a computer with an Internet connection, and, for users, a personal cell phone for encrypted log-on information. The staff members who contributed to an ICP were drawn from different professional groups in a variety of health and social care organizations, so we have referred to them using the general term "care professionals". This term applies both to the coordinators for RGs and to the other professionals listed in Table 1. The care professionals' background was health education at the bachelor's level or higher. Most of the professionals were nurses; some were teachers and preschool teachers, social care officers, and physiotherapists; and a few were physicians and psychologists. There are some instances in this article when a distinction must be made between the RG coordinators and other professionals, who are then described as "non-coordinators".

Local project leaders at the three SamPro project sites recruited participants and established RGs in their municipalities. The participants, both users and care professionals, were trained in use of the SamPro tool for managing the ICP for half a day, with individual follow-up if necessary. The system vendor offered helpdesk services to the project leaders. No participants withdrew from the study.

Ethical considerations

We obtained permission for the study from the Norwegian Social Science Data Services, and reported the study to the Regional Committee for Medical Research Ethics. All personal identifiers have been removed or disguised, so the patients/persons described are not identifiable and cannot be identified through the details of the story. Patients or parents of child patients in the pilot testing project were informed about the study when they joined the testing project, and they were asked to sign consent forms for participating in this study. The patients and parents controlled the e-ICP system access for included RG participants and researchers. Mental health nurses with dialogical competence interviewed vulnerable adult patients.

Data collection and analysis

We collected data through individual interviews and focus-group interviews, as shown in Table 2. The interviews were based on semistructured interview guides.[31–33] Table 3 shows the main questions in the interview guides.

The time spent in individual interviews ranged between 10 minutes and 3 hours; on average they took 1.5 hours. The shorter interviews were limited by the user's condition at the time. In one interview, both parents of a child user participated. Individual interviews were conducted at the end of the study period.[34] Six focus-group interviews, three in each of the groups, were conducted during the autumn of 2005. Each focus-group interview lasted approximately 2 hours. The authors of this paper conducted the interviews.

Video recording was preferred for practical transcription reasons, but a few individual interviews were tape-recorded due to available equipment in these situations. All interviews were transcribed verbatim, and discussed among the researchers afterward.

Data analysis was performed using systematic text condensation, according to the stepwise model presented

Table 2 Study context and data collection

Study context	Informants	Sample	Data
Site 1: County 1: two town municipalities[a]	Adult users	10	Individual interviews
One rural municipality	Coordinators	1	
	Care professionals	2	
Site 2: County 2: one city municipality[a]	Parents of child users	4	
	Coordinators	2	
	Care professionals	1	
Site 3: County 3: one town municipality[a]	Parents of child users	1	
	Coordinators	1	
	Care professionals	1	
Site 1: County 1	Coordinators	8 persons in 2 different groups	Focus group interviews

Notes: [a]Town municipality, <50,000 inhabitants; city municipality, >50,000 inhabitants.

Table 3 Interview guide, key questions

Individual interviews	How do you regard your role as a user/care professional in relation to the health care system? Do you think your role has changed through use of the SamPro system?
Focus-group interviews	How did the coordinators and users collaborate in the ICP? What challenges did they experience? Did the user have a greater co-decision-making role when using the e-ICP?

Abbreviations: ICP, individual care plan; e-ICP, electronic individual care plan.

by Malterud.[35] The analysis started with naive reading of the set of the transcribed individual interviews and of the focus-group interviews separately, one by one, to gain a general impression and to discern the preliminary themes. Examples of preliminary themes included *To take responsibility or be responsible*, *To be in control*, *Coping in life*.

From the naive reading, "meaning units" representative of the research questions were found, for example,

> As long as you dare to write down the bad things you clearly see what is good and what is bad.
>
> Being aware of what is important to work with.

The interviews and focus-group interviews were further analyzed as a single coherent piece of text. From the meaning units and the preliminary themes, the coding continued into themes, with small changes from the preliminary outline.

Themes were further condensed into overarching themes, and detailed with subgroups. Four main themes were generated from the text without any theoretical criteria:

- the proactive users speaking about themselves and their care professionals;
- the reluctant users speaking about themselves and their care professionals;
- the proactive care professionals speaking about themselves and their users;
- the reluctant care professionals speaking about themselves and their users.

Finally, the analysis was completed, presenting the generated descriptions, with quotations from the integrated text illustrating the subthemes. The main themes form the structure of the presentation of the results.

Results

The mental health patients were aged between 21 and 68; five had completed military service, three had a part-time job, and only one had had further education after secondary school. Participating parents were aged from 30 to 50; all except one had higher education and all were in part-time or full-time jobs. Both users and care professionals expressed clear opinions about their own role as participants in use of the e-ICP as well as their RG partners; users about care professionals; and care professionals about users. No coherence was found between the users' sociodemographics/illness symptoms and activity in the e-ICP. In the following paragraphs, the subthemes are shown in *italics* to improve readability.

The proactive user

The proactive users generally emphasized the benefits of online access to the care plan and to the process overview. They participated actively in the collaboration by sending SMS messages to their RG participants, reading and editing their plan or commenting on care professionals' planned actions.

The adult users used phrases such as

> I am my own boss now
>
> or
>
> The game is in my part of the field.

They expressed a sense of comfort and safety in the situation, and a perception of greater control. Two adult users even wanted to be their own coordinators, as they felt that by using this tool they could manage their own care planning.

The proactive user roles were grouped into themes such as *co-responsibility user, everyday user*, and *self-therapeutic user*. Following examples indicate how these groups were manifested. Data from the interviews showed that a number of users started to act more proactively in the determination of their own plan, in different ways. Some focused on their everyday life, for example, making appointments for the next RG meeting by using the internal messaging module. These *everyday users* generally sought to make just enough use of the SamPro system to benefit from minimal expenditure of time and effort.

In contrast, a couple of adult *self-therapeutic users* used the plan to write down their psychological problems and difficult feelings, which they then brought into conversations with their coordinators or psychotherapist:

> I write it down in my plan when I want to! I just get it right out of my head! Wow.

Proactive users were aware that greater participation was accompanied by an increased level of joint responsibility. The *co-responsible users* took a leading part in system implementation and planning processes. As both users and care professionals participated in joint online process and system training, users sometimes saw *a lack of skills* among professionals involved both in care planning and in computing. Many users had just as good, or better, knowledge of computer and Internet use as had the care professionals. In a few RGs, these users took the role of system superusers:

> Don't you worry: I will come to an evening shift and teach you how to use this tool.

Users stated that, in well-functioning groups, care professionals took initiatives and responded to requests in a satisfying way. They *trusted the care professionals* involved and participated according to their own needs and wishes.

When care professionals withdrew from their part of the planning, proactive users took on tasks and responsibility normally vested in the professionals. Users also took responsibility for their impact on the working hours of the professionals by their awareness of SMS availability, taking into consideration that care professionals might not be willing to respond to messages when they were off duty. *Planning disagreements* among care professionals also became more visible, not just in meetings but now also in the web-based activities. Users accessed logs and commented on whether or not the professionals participated in plan collaboration as expected.

Some users therefore compensated by increasing their participation in their own RGs due to a *lack of trust* in the professionals involved.

The proactive care professional

Generally, the care professionals involved in the RGs did not regard their role as much changed by their engagement in web-based collaboration. They saw themselves as being the main initiative takers in the planning process, as specified by the regulations relating to ICP. They took on the *plan-managing role* as usual, and described their consciousness of this role, taking the professional role in planning appropriate to their expertise and position. They perceived their performance of documentation tasks as a means of ensuring appropriate provision of care. The coordinator took responsibility for the completeness of the overall plan, and non-coordinators for their specific parts. There was *diversity of opinion* about the distribution of responsibility and workload between coordinators and non-coordinating professionals. The coordinators said they had the main collaborative responsibility in their RG, but they had to work hard to get their colleagues involved in collaboration, even though everyone had equal online access and responsibility to carry out the planned activities. They felt a *solitary responsibility* for keeping collaboration going and for documenting the tasks within the plan. The coordinators had an additional role as *system superusers,* and they were in charge of system training in their RG.

If they lacked knowledge about system use or planning, they actively searched for support to learn more about how to plan properly using this web-based tool. They said that the extra work led to long working hours. They asked for a better distribution of responsibility among all care professionals involved.

The proactive care professionals generally expressed *confidence in the users'* role and participation. They did not perceive users with greater competence in using computers than their own as threatening their professional role in the collaboration. Nevertheless, care professionals took on a *protective role* as they expressed that they were worried about some users' capacity and disclosure; they were afraid users would reveal more private information in the plan documentation than they would be comfortable with later.

The proactive care professionals said they worked hard to *motivate users* to take part in the collaborative process. They wanted users to document their real needs and goals, but they often felt they had little success in engaging users to take ownership of the planning process.

Web-based collaboration extended their communication opportunities with their fellow RG participants, and care professionals liked this facility. However, they still seemed to prefer using the established communication lines that they had been used to before e-ICP was introduced: message books in the kindergarten, telephone calls, ordinary SMS, and postal letters.

The reluctant user

Reluctant users generally commented that they did not reject the web-based tool as a solution for care planning, but looked forward to a future, better-functioning tool. In the meantime they preferred or felt forced to stay reluctantly in a role of *being uncommitted.*

Exhausted reluctant users regarded e-ICP participation as an extra burden in their lives. When adult users could not manage to obtain access to the system or they had problems using the system for their own purposes, they *felt helpless.* In some cases, this feeling of helplessness was due to technical issues, a lack of expertise, or lack of coping with their illness. The group of parents in particular expressed that they had little extra time to spend:

> This is not going to be another Net banking solution where I do the work for them

Adult users also expressed a feeling of *decreased coping* if in difficult periods they were not capable of the level of planning participation that they expected of themselves. Like parents with high care burdens, these users showed less interest in plan management. Their energies were reserved for everyday coping, and an active role in web-based planning became an extra burden.

In some RGs, adult users felt *overruled* by care professionals in their planning efforts. A few without a computer at home even claimed that:

> They don't let me see my plan.

Users also experienced that a few care professionals declined to participate because they found receiving SMSs at all hours a burden, even when no reply was needed. In several instances, users had to put pressure on care professionals to make them take on their commitment to care planning. In these situations, users felt they were *ignored* by the professionals involved.

The reluctant care professional

Several care professionals said they felt uncomfortable in their lack of expertise in using this new tool. After training, they rarely accessed the tool; they became passive in planning, and forgot how to use the SamPro system in the interval between one log-on and the next. They were *uncommitted* to the planning process in their RG. Non-coordinating professionals relied extensively on the plan coordinator. Reluctant care professionals focused on the SMS availability they were exposed to; they felt their working time, in particular, their private life and spare time were being interrupted. The data showed that reluctant care professionals did not pay attention to users' participation in e-ICP planning or to users' coping in the process. Nor did these care professionals reflect on the need of less skilled users for training or follow-up. Users were regarded as having *no plan ownership.*

These care professionals doubted that adult users understood the motivation for using the web-based tool, and believed they could only cope with simple tasks in planning. Reluctant care professionals stated that users involved had a *"no-ownership role"* in their own plan.

Discussion

The main finding in this study was that the roles of both users and care professionals were challenged in terms of the understanding of the patient/professional role in their e-ICP interactions. Some of the users and the professionals developed a "proactive role" enabled by the possibilities of the new tool, which influenced the plan process. Others remained in a passive role, "reluctant users" or "reluctant care professionals", in spite of web-based collaboration opportunities. The data also showed a correspondence between the different user and care professional roles, but no differences connected to age, sex, or levels of education. Figure 1 provides a summary model of the function of care providers and users. Arrows indicate the potential relationships between users and care professionals and what attitudes they showed toward a web-based collaboration.

We saw the greatest transfer of power in the patient/provider relationship in the group we called "proactive users". This power transition was made possible by two main preconditions: 1) the new cross-organizational model of care that necessitated preparation of a multidisciplinary and collaborative ICP for service, enabling user involvement in ICP development,[8] and 2) the use of SamPro, which, for the proactive users and care professionals, stimulated activity and collaboration as well as knowledge and shared responsibility. Both knowledge and responsibility are important elements in the transition of power toward patient empowerment.[19] Using SamPro enabled some users to work on their plan both independently and together with their care professionals. Through the web-based access to the plan documents and to the planning process in the SamPro system, a proactive user might run the planning with little support from the care professionals. This was also the situation in some RGs, where the professionals involved were not synchronized in their planning activities, and users assumed some of the responsibilities for coordinating the plan. We even saw instances where users had effectively become their own plan coordinators.[12] Users took on a proactive planning role for different reasons; some simply had an attitude of taking responsibility, for some there was a need for everyday scheduling of activities, and others found it therapeutic. Whatever the reason, these users took some control of the planning, gained a sense of ownership of their plan, and acted as empowered users. All these examples illustrate forms of power transition.

Planning was accomplished well in RGs established between proactive users and proactive care professionals, taking account of factors that were important to the user and to other participants. Users were enabled to conduct planning by assuming co-responsibility to whatever extent that they wanted or needed. This process was complemented by care professionals who carried their part of the planning

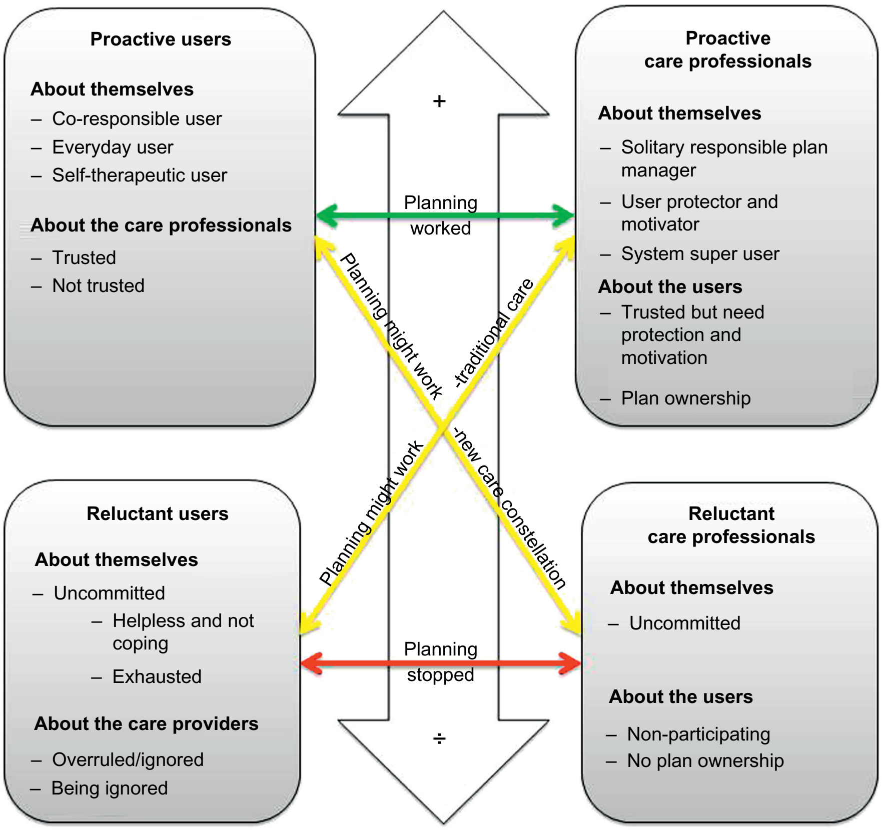

Figure 1 Transition of power in care professional versus user roles in e-ICP.
Abbreviation: e-ICP, electronic individual care plan.

responsibility in terms of various co-responsibility models supporting both users who preferred a self-therapeutic approach and those who focused on daily planning. This flexibility was possible due to the organizational model that web-based access enabled. All the participants, users as well as care professionals, could access the shared collaborative platform and the documentation involved. This flexibility led to the development of reciprocal confidence and trust between the different participants involved in each e-ICP, which resulted in more equality of power. This constellation met the requirements of both ICP thinking and the prevailing political ideal of user involvement and patient empowerment, with the care professionals taking on a flexible, supportive, coaching role.[36]

As has been noted in the literature,[25] this transition of power depended on either users or their collaborating care professionals developing the technical skills required, and acting with skilled role performance and competence.[20] It was also necessary that both parties saw the plan process as meaningful. To be system superusers was an additional task or function for both users and professionals; this was not known from previous patient–professional constellations. By taking a proactive attitude, they accomplished this extra task and learned from whichever participant was most skilled in the use of web-based systems and the e-ICP, regardless of whether this skilled person had the role of being the therapeutic expert or the lay user in the care setting. When users took on the superuser task, we saw the development of new performance and user behavior, and a power transition took place. The care professionals, who had been expected to be the expert in the relationship, shifted power toward the lay participant, the user. The patient became an "expert patient",[37] being the group member who was most skilled and competent in ICT system use.

However, when the web-based tool did not function well, and the participants could not realize the potential of the system or the users were too exhausted or too ill to use the tool actively, no transfer of power took place. Under such circumstances, SamPro could be a hindrance for some reluctant participants, and patients might be less instead of more empowered. The tasks of the system superuser increased the workload of the care professionals who undertook them. This sometimes increased reluctance among those who did not have the knowledge or skills to commit to this new task. For care professionals, exposure to SMS alerts for system updates while they were off duty could increase reluctance. The research of Schumacher and Meleis supports this finding, indicating that the achievement of skilled performance, competence, and new behavior required is necessary for successful transition.[38] This requirement might be an ongoing iterative process, as new technology becomes available and legislation is subsequently updated to address new ways of documenting and communicating patient information.

The data showed that in instances where there was low commitment from both parties, the planning process did not have the driving force on which collaborative processes aiming for growth depend. As some users in this "reluctant" constellation were simply ignored by the uncommitted care professionals, this strengthened the negative attitude to planning in RGs.

Despite the new culture of increased patient empowerment that has developed in recent years and the new opportunities available to users through the web-based solution, users could not be expected to take over planning tasks that were the responsibility of care professionals.[39] These reluctant users did not have the energy or courage to take on the task of leading their own care planning without support from the care professionals involved. As no one carried out the planning tasks, planning stopped. The expectation had been that ICPs would be established for approximately 3% of the population in Norway, but studies showed an increase only from 0.5% in 2005 to 0.58% in 2010.[7,38] Professional reluctance, whatever the reasons, might be a problem hindering the expected growth in plans, and the low number does not seem to have been addressed through any legal or organizational reaction.

In paternalistic power distribution in health and social care, the professionals involved are the experts and they supervise the implementation of activities identified for the care users for whom they are responsible.[39,40] Care professionals are in charge of the process, and users receive and accept the care program, based on the professionals' decisions. The connectivity line in Figure 1 between a proactive care professional and a reluctant user follows this paternalistic approach.[41] The care users explained to the interviewers that they did not have the capacity needed for proactive participation and consequently they left the care planning to the professionals. We saw in our data that proactive care professionals compensated by taking on actions on behalf of the reluctant users. This behavior does meet *one* of the purposes of an ICP: to establish a planning group to ease the life situation of the users. In groups where users felt well taken care of, this asynchronous relationship between the user and the care professional might work well, as long as users felt that their needs and requirements were met as they wanted.

We also identified users who felt that they were ignored or overruled by their proactive care professionals. Plans might still be made, even though the users felt they had little voice in the planning process.[42] This reaction of resignation in response to overruling or ignorance from care professionals has also been reported in and is also recognizable in previous research.[43,44] Such negative feelings are barriers to participation[25] and hindrances to power transition.

A nontraditional constellation and a change to former role interpretation were seen in the pairing of a reluctant care professional and a proactive user. In this constellation, the reluctant care professional did not take the expected responsibility or showed a laissez-faire attitude through their lack of commitment in planning. Their partner, the proactive user, was taking on greater planning responsibility than had been intended in the conception of ICPs.

The model of complementary roles of ICP presented in Figure 1 shows various constellations of user involvement, attitudes of care professionals, and power transition. Our data did not show that users wanted the same level of formal responsibility as was required of the care professionals. They wanted to trust the professionals to do their part of the job, but took more initiatives and control than known from other health care constellations. Web-based access made this possible, or compensation for a lack of professional initiatives made it necessary. The user's level of coping and having the time or energy to commit were essential in this instance. Care professionals stated that they were aware of being in charge of the process, even in instances where users stated that the care professionals had not always acted in accordance with their level of responsibility. Here, the *content* of the roles was in transition, bringing more power to the users involved. Instances when users were ignored and were not permitted to see their care plan, while they knew that it should have been available to them on the Internet, could be understood as a clear demonstration of professional power at the expense of user empowerment. The *other main purpose* of ICP is to increase patient empowerment.[8,39] Even though the main intention of patient empowerment is to increase user involvement and self-determination, this empowerment role may also be interpreted as involving the right *not* to participate actively in circumstances where the user's level of fatigue or other lack of capacity is too great.[45] Users' active choice of noninvolvement is not often discussed in health care politics, which now emphasizes patient empowerment and user involvement.[46]

Discussions of the need for or use of paternalism or professional power in care in relation to patient autonomy and empowerment are common in nursing professional theory.[47–49] Patient empowerment generally refers to the increase in the strengths of marginalized people, involving development of confidence in their own capacities. Empowerment refers here to the transfer of at least some decision-making power, as we saw in "proactive users". Unless users have the opportunity to make decisions over their own lives, they cannot become independent.[17] That means that care professionals have to take a step back, limiting their own expectations, and acting more like an equal partner. In international literature, the partner role is presented as an important prerequisite for user cooperation.[50–53] Daniel describes partnership as a "power with-relation", where integrity and more strength and ability to carry out things are preserved, while equivalence in authority and benefits is maintained.[54] In the present study, the researcher's collaboration and follow-up support of the individual user can coincide with the description of taking the role of a partner. The results show that user education contributed to an increase in knowledge and skills, which in turn resulted in users who were more knowledgeable. Some users went through a change from being passive recipients to becoming more active partners.

Limitations

We argue that the validity of this qualitative study relies on the fact that the data answer the research question and that the results correspond with findings from international research. Strengths of the study include the use of both individual and focus-group interviews and the authors' joint activity in performing the steps in the data analysis.

Some weaknesses may be the small sample of informants and the type of participating RGs, representing only two patient groups in one of four health trusts in Norway, as well as the age of the data. The system testing and implementation process limited the possible number of participants due to the demanding schedule of testing and the follow-up needs among the participants. The findings cannot therefore be generalized. However, results from recent studies in Norway[13,42,55,56] make our findings credible in terms of both the context and date of this study. The use of multiple sites was not seen as a weakness because both system testing and data collection were coordinated. The variation found was identified as either individual or related to the patient groups (children/adults), but not to the testing sites. The care professionals and users interviewed were all participating in the SamPro implementation project and they might therefore be more positive about e-ICP.

Conclusion

In the use of a web-based system for care plan collaboration, we found that both users and care professionals took upon themselves the role of being proactive or reluctant participants in the planning process, which can be interpreted as a role transition through transition of power, eg, knowledge, responsibility, and a new function. A new pattern revealed in this study was the proactive user who could make planning work despite being paired with reluctant care professionals if the user was given web-based access to the planning tool and their own plan documents. The knowledge from this study might be used to develop a new understanding of how role content and power or the user/care provider relationship can be challenged through equal access by users and care professionals to health care documentation and planning tools. The study also shows the need for technical knowledge and skills among participants in web-based planning. When this was missing, no power transition took place.

More research should be encouraged in order to explore further the tendencies we have revealed; the reasons for proactivity and reluctance should be investigated in greater depth, together with ways to ensure that patients do not become even more isolated or neglected by being paired with nonengaging carers. It is also necessary to determine whether such web-based care planning tools are more suitable for some groups of users than for others. We therefore suggest a more rigorously designed study of how users' sociodemographics (such as sex, age, and level of education), disease, and functional limitations might influence the human–human interaction as well as the power transition and users' empowerment in the context of e-ICP.

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Disclosure

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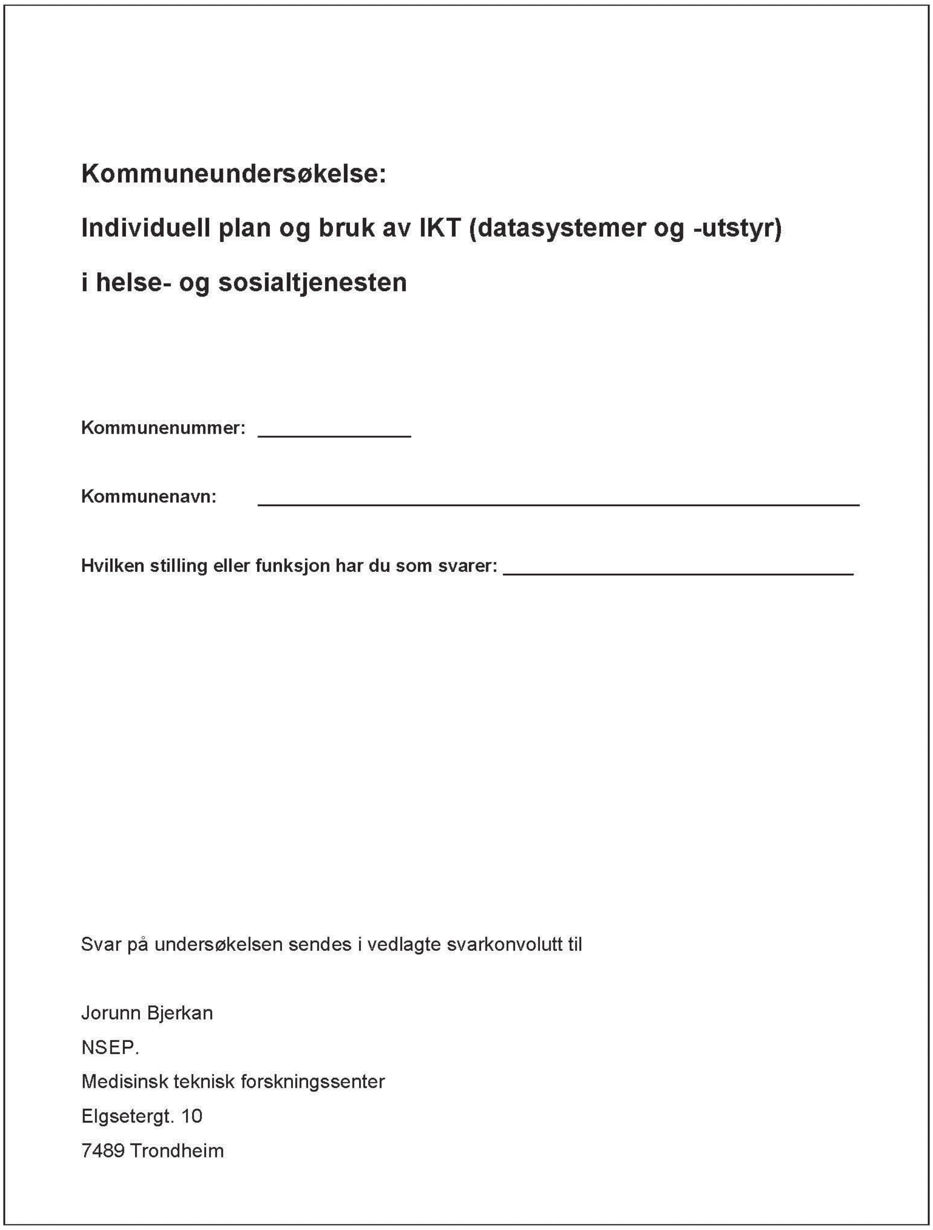
Appendix

Appendix 1: municipal questionnaire in study I.



Kommuneundersøkelse:
Individuell plan og bruk av IKT (datasystemer og -utstyr) i helse- og sosialtjenesten

Kommunenummer: _______________

Kommunenavn: ____

Hvilken stilling eller funksjon har du som svarer: __________________________________

Svar på undersøkelsen sendes i vedlagte svarkonvolutt til

Jorunn Bjerkan
NSEP.
Medisinsk teknisk forskningssenter
Elgsetergt. 10
7489 Trondheim

Generelt om individuell plan

1 ***Hvor mange innbyggere i kommunen har pr. i dag en individuell plan i funksjon?***

(skriv 0 hvis ordningen ikke er tatt i bruk)

	ja	nei	vet ikke
Har kommunen oversikt over antall planer?	☐	☐	☐
(Anslagsvis) antall planer	☐		

►Hvis svaret er 0, gå videre til spørsmål 10, 11, 12 og 13..

2 ***Hvem setter vanligvis i gang en planprosess i forhold til kommunens innbyggere?***

	-Ofte	Av og til	Sjelden
Bruker eller pårørende ved å etterspørre plan	☐	☐	☐
Kommunens helsetjeneste	☐	☐	☐
Kommunens sosialtjeneste	☐	☐	☐
Kommunens barnevernstjeneste	☐	☐	☐
Kommunens servicekontor	☐	☐	☐
Kommunens oppvekstsenter/ skoler eller barnehager	☐	☐	☐
PP-tjenesten	☐	☐	☐
Fastlegen	☐	☐	☐
Kommunens flyktningetjeneste	☐	☐	☐
Spesialisthelsetjenesten	☐	☐	☐

	-Ofte	Av og til	Sjelden
Aetat	☐	☐	☐
Trygdeetaten	☐	☐	☐
Annet sted	☐	☐	☐

Hvor?

3 Hvilke enheter i kommunen deltar i arbeidet med individuelle planer?

	-Ofte	Av og til	Sjelden
Pleie- og omsorgstjenesten	☐	☐	☐
Habiliterings- og rehabiliteringstjenesten	☐	☐	☐
Sosialtjenesten	☐	☐	☐
Barnevernstjenesten	☐	☐	☐
Helsestasjonstjenesten	☐	☐	☐
Fastlegene	☐	☐	☐
Flyktningetjenesten	☐	☐	☐
Barnehagene	☐	☐	☐
Skolene	☐	☐	☐
Andre	☐	☐	☐

Hvem?

4 Blir det oppnevnt en ansvarlig tjenesteyter, koordinator, i de individuelle planprosessene?

Ja, alltid	☐
Ofte	☐
Av og til	☐
Sjelden	☐
Nei, aldri	☐

►Hopp over spørsmål 5 hvis du svarte nei på spørsmål. 4.

5 Hvis ansvarlig tjenesteyter / koordinator oppnevnes, hvem innehar oppgaven?

	-Ofte	Av og til	Sjelden
Bruker selv eller pårørende/ foresatte	☐	☐	☐
Sykepleiere / vernepleiere	☐	☐	☐
Sosialkuratorer	☐	☐	☐
Lærere	☐	☐	☐
Førskolelærere i barnehager	☐	☐	☐
Helsesøstere	☐	☐	☐
Fysioterapeuter / ergoterapeuter	☐	☐	☐
Fastlegen	☐	☐	☐
Ansatte i spesialisthelsetjenesten	☐	☐	☐
Andre	☐	☐	☐

Hvem?

6 *Opprettes det ansvarsgruppe i forbindelse med oppstart av ny plan?*

Ja, alltid	☐
Ofte	☐
Av og til	☐
Sjelden	☐
Nei, Aldri	☐

7 *Benyttes det strukturerte maler i forbindelse med utarbeidelse av individuell plan?*

Èn fast mal	☐
Flere ulike maler	☐
Ingen maler	☐
Ulik praksis: noen benytter maler, andre ikke	☐

8 Samarbeider kommunen med andre instanser om individuell plan?

	-Ofte	Av og til	Sjelden
Fastlegen	☐	☐	☐
Spesialisthelsetjenesten	☐	☐	☐
Privatpersoner (for eksempel støttekontakter)	☐	☐	☐
PP-tjenesten	☐	☐	☐
Fylkesmannen / Fylkeslegen	☐	☐	☐
Videregående skoler	☐	☐	☐
Aetat	☐	☐	☐
Trygdeetaten	☐	☐	☐
Hjelpemiddelsentralen	☐	☐	☐
Private virksomheter eller institusjoner	☐	☐	☐
Andre	☐	☐	☐

Hvem?

9 *Samhandling om individuell plan:*

	Alltid	Ofte	Av og til	Sjelden	Aldri
Sentrale aktører <u>møtes</u> for å lage en ny plan	☐	☐	☐	☐	☐
Plan utformes av èn tjenesteyter alene	☐	☐	☐	☐	☐
Samarbeid rundt planutforming skjer ved hjelp av brevveksling/ sirkulasjon av planen	☐	☐	☐	☐	☐
Samarbeid rundt planutforming skjer ved hjelp av e-post	☐	☐	☐	☐	☐
Samarbeid rundt planutforming skjer ved hjelp av telefon	☐	☐	☐	☐	☐
Planer oppdateres en gang i året eller mer	☐	☐	☐	☐	☐
Planer evalueres i møte en gang i året eller mer	☐	☐	☐	☐	☐
Medvirkende aktører i en plan får tilsendt kopi av oppdaterte planer	☐	☐	☐	☐	☐
Andre samhandlingsformer	☐	☐	☐	☐	☐

Hvilke?

10 ***I hvor stor grad har disse aktørene fått opplæring i utforming og bruk av individuell plan?***

	I stor grad	I noen grad	I liten grad	Vet ikke
Ledelsen i helse- og sosialsektoren	☐	☐	☐	☐
Mellomledere i helse- og sosialsektoren	☐	☐	☐	☐
Sykepleiere / vernepleiere i pasientrettet arbeid	☐	☐	☐	☐
Lærere	☐	☐	☐	☐
Førskolelærere i barnehager	☐	☐	☐	☐
Helsesøstere	☐	☐	☐	☐
Fysioterapeuter / ergoterapeuter	☐	☐	☐	☐
Kontormedarbeidere	☐	☐	☐	☐
Sosialkuratorer	☐	☐	☐	☐
Fagpersonell i barnevernstjenesten	☐	☐	☐	☐
Fastleger	☐	☐	☐	☐
Kontormedarbeidere i helse- og sosialsektoren	☐	☐	☐	☐
Koordinatorer spesielt	☐	☐	☐	☐
Andre aktører	☐	☐	☐	☐

Hvem?

Bruk av IKT

11 Hvilke av disse gruppene bruker jevnlig IKT- verktøy i sin arbeidsdag?

	Fag-syst-emer	Kontor-støtte-systemer	Vet ikke
Ledelsen i helse- og sosialsektoren	☐	☐	☐
Mellomledere i helse- og sosialsektoren	☐	☐	☐
Sykepleiere / vernepleiere i pasientrettet arbeid	☐	☐	☐
Lærere	☐	☐	☐
Førskolelærere i barnehager	☐	☐	☐
Helsesøstere	☐	☐	☐
Fysioterapeuter / ergoterapeuter	☐	☐	☐
Kontormedarbeidere i helse- og sosialsektoren	☐	☐	☐
Sosialkuratorer	☐	☐	☐
Fagpersonell i barnevernstjenesten	☐	☐	☐
Fastleger	☐	☐	☐
Andre	☐	☐	☐

Hvem?

12 Hvilke av disse gruppene har tilgang til internett på sin arbeidsplass?

	Ja	Nei	Vet ikke
Ledelsen i helse- og sosialsektoren	☐	☐	☐
Mellomledere i helse- og sosialsektoren	☐	☐	☐
Sykepleiere / vernepleiere i pasientrettet arbeid	☐	☐	☐
Lærere	☐	☐	☐
Førskolelærere i barnehager	☐	☐	☐
Helsesøstere	☐	☐	☐
Fysioterapeuter / ergoterapeuter	☐	☐	☐
Kontormedarbeidere i helse –og sosialsektoren	☐	☐	☐
Sosialkuratorer	☐	☐	☐
Fagpersonell i barnevernstjenesten	☐	☐	☐
Fastleger	☐	☐	☐
Andre aktører i helse- og sosialsektoren	☐	☐	☐

Hvem?

IKT og Individuell Plan

13 ***Bruk av datastøtteverktøy for å lage og oppdatere individuelle planer:***

	Alltid	Ofte	Av og til	Sjelden	Aldri
Individuell plan lages ved hjelp av et EPJ-system*	☐	☐	☐	☐	☐
IP* lages ved hjelp av egenutviklet IKT-system	☐	☐	☐	☐	☐
IP lages ved hjelp av tekstbehandlingssystem	☐	☐	☐	☐	☐
Vi skriver individuelle planer for hånd	☐	☐	☐	☐	☐

*EPJ-system: elektronisk pasientjournal- system

*IP: Individuell plan

14 ***Hvilke utfordringer er etter din mening de største når det gjelder utforming og bruk av individuell plan?***

15 ***Har du forslag til hvordan disse utfordringene kan løses?***

Takk for at du tok deg tid til å svare på spørreskjemaet!

Appendix 2: interview guide for study II.

Intervjuguide, semistrukturert intervju, SamPro/egenjournal:

Generell oppstart intervju:

Bakgrunn for intervju, oss selv, aster/PHD-prosjekter: SamPro og tilgangskontrollsystem i egenjournaler, behandling/oppbevaring av materiale, bruk av lyd/video-opptak, frivillighet til å besvare enkelte spm./områder.

Om SamPro og roller

Deltakernes opprinnelige roller, bakgrunn, særinteresser og egenskaper påvirker prosessen med, og utformingen av nett –IP.

1. Kan du si litt om hvordan du oppfatter din rolle som bruker/profesjonell utøver i forhold til brukere/hjelpeapparat til vanlig?
    i. Hvordan oppfatter du din rolle i forbindelse med bruk av Sampro?
    ii. annerledes enn i andre sammenhenger med pasienter/klienter/hjelpeapparat?
    iii. Synes du dette har vært med på å påvirke utviklingen av SamPro på noen måte?
    iv. Hvordan synes du leverandørens kunnskap om IP er? deres påvirkning av verktøyet
    v. Leverandørens påvirkning av verktøysutviklingen på bakgrunn av det de kan?

2. Tilgjengelighet/reservasjon /Sikkerhet og personvern
    i. Hvor åpen eller begrenset synes du tilgjengeligheten i SamPro bør være?

    ii. Har du foreslått/ fått gehør for dette i SamPro?
    iii. Er dette det samme som i andre sammenhenger der du er bruker/profesjonell utøver også?

Kommunikasjonskanal og egenjournal:

Tjenestemottakere utvider bruksområdet i planverktøyet utover intensjonen med individuell plan i retning generell kommunikasjonskanal og egenjournal.

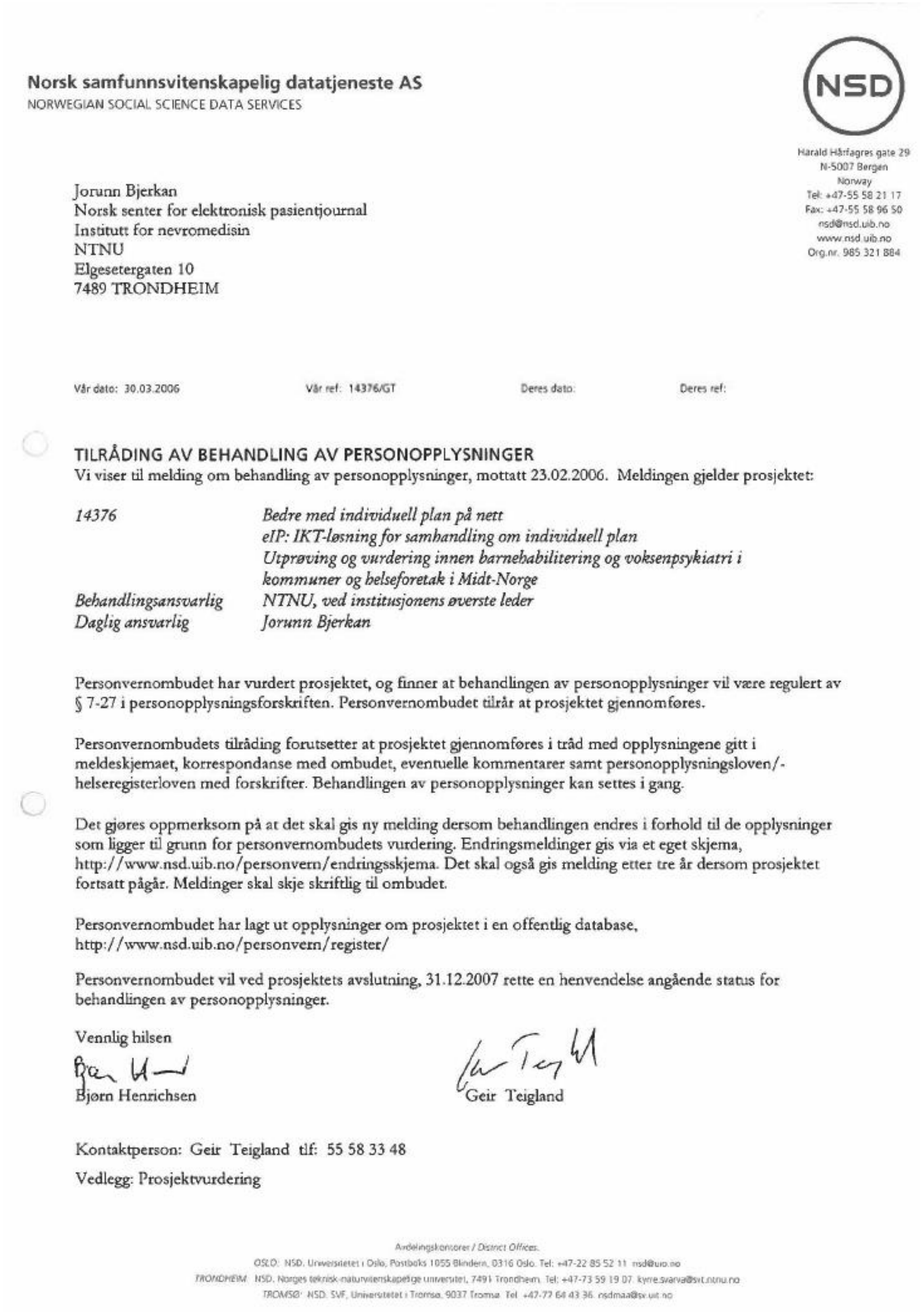
Internettbasert individuell plan endrer dokumentasjonen i underliggende fagsystemer, spesielt individuell opplæringsplan (IOP) og elektronisk pasientjournal (EPJ)

3. Bruker du sampro til noe annet/mer enn det som ligger i IP?
    i. Hva, på hvilken måte, hvordan, hva fører det til?

4. Blir dokumentasjonen i de andre systemene annerledes nå når man har tatt i bruk SamPro?
    i. EPJ/IOP/
    ii. Overføres dokumentasjon?

5. Synes du muligheten til kontakt i SamPro gjør forholdet mellom brukere/hjelpeapparat annerledes på noe vis?
    i. på hvilken måte, hvordan, hva fører det til?

Appendix 3: approval from NSD and REK.



Norsk samfunnsvitenskapelig datatjeneste AS
NORWEGIAN SOCIAL SCIENCE DATA SERVICES

Harald Hårfagres gate 29
N-5007 Bergen
Norway
Tel: +47-55 58 21 17
Fax: +47-55 58 96 50
nsd@nsd.uib.no
www.nsd.uib.no
Org.nr. 985 321 884

Jorunn Bjerkan
Norsk senter for elektronisk pasientjournal
Institutt for nevromedisin
NTNU
Elgesetergaten 10
7489 TRONDHEIM

Vår dato: 30.03.2006 Vår ref: 14376/GT Deres dato: Deres ref:

TILRÅDING AV BEHANDLING AV PERSONOPPLYSNINGER

Vi viser til melding om behandling av personopplysninger, mottatt 23.02.2006. Meldingen gjelder prosjektet:

14376	*Bedre med individuell plan på nett* *eIP: IKT-løsning for samhandling om individuell plan* *Utprøving og vurdering innen barnehabilitering og voksenpsykiatri i kommuner og helseforetak i Midt-Norge*
Behandlingsansvarlig	*NTNU, ved institusjonens øverste leder*
Daglig ansvarlig	*Jorunn Bjerkan*

Personvernombudet har vurdert prosjektet, og finner at behandlingen av personopplysninger vil være regulert av § 7-27 i personopplysningsforskriften. Personvernombudet tilrår at prosjektet gjennomføres.

Personvernombudets tilråding forutsetter at prosjektet gjennomføres i tråd med opplysningene gitt i meldeskjemaet, korrespondanse med ombudet, eventuelle kommentarer samt personopplysningsloven/-helseregisterloven med forskrifter. Behandlingen av personopplysninger kan settes i gang.

Det gjøres oppmerksom på at det skal gis ny melding dersom behandlingen endres i forhold til de opplysninger som ligger til grunn for personvernombudets vurdering. Endringsmeldinger gis via et eget skjema, http://www.nsd.uib.no/personvern/endringsskjema. Det skal også gis melding etter tre år dersom prosjektet fortsatt pågår. Meldinger skal skje skriftlig til ombudet.

Personvernombudet har lagt ut opplysninger om prosjektet i en offentlig database, http://www.nsd.uib.no/personvern/register/

Personvernombudet vil ved prosjektets avslutning, 31.12.2007 rette en henvendelse angående status for behandlingen av personopplysninger.

Vennlig hilsen

Bjørn Henrichsen Geir Teigland

Kontaktperson: Geir Teigland tlf: 55 58 33 48

Vedlegg: Prosjektvurdering

Personvernombudet for forskning, NSD

Prosjektvurdering - Kommentar

14376

Personvernombudet har vurdert prosjektmeldingen og finner at behandlingen kan finne sted med hjemmel i personopplysningsloven (POL) §§ 8 første ledd og 9 a.

Informasjonsskrivet forutsettes endret i tråd med ombudets kommentarer. Det bes om at kopi av endelig versjon av skrivet oversendes. Personvernombudet forutsetter at helsepersonell som deltar i studien mottar tilsvarende informasjon.

Det forutsettes videre at prosjektet tilrådes av Regional komité for medisinsk forskningsetikk (REK) før det settes i gang. Ombudet ber om å få tilsendt kopi av REKs tilrådning.

Ved prosjektslutt 31.12.2007 skal datamaterialet anonymiseres ved at direkte og indirekte personidentifiserende opplysninger slettes eller omkodes (grovkategoriseres), bilde- og lydopptak destrueres.

NTNU
Norges teknisk-naturvitenskapelige universitet

Det medisinske fakultet
Regional komite for medisinsk forskningsetikk
Helseregion Midt-Norge

Professor Anders Grimsmo

Saksbehandler
Rådgiver Arild Hals
Telefon 73 86 7152
Fax 73 86 72 89
Epost:arild.hals@ntnu.no
rek-4@ntnu.no
Postadresse: Det medisinske fakultet
Medisinsk teknisk forskningssenter
7489 Trondheim
Besøksadr: Kreftbygget 5.etg
St. Olavs Hospital

Vår dato:	Vår ref.:	Deres dato:	Deres ref:
06.10.06	4.2006.2915		

Individuell plan på nett. Nett-IP: IKT-løsning for samhandling om individuell plan - Utprøving og vurdering innen barnehabilitering og voksenpsykiatri i kommuner og helseforetak i Midt-Norge

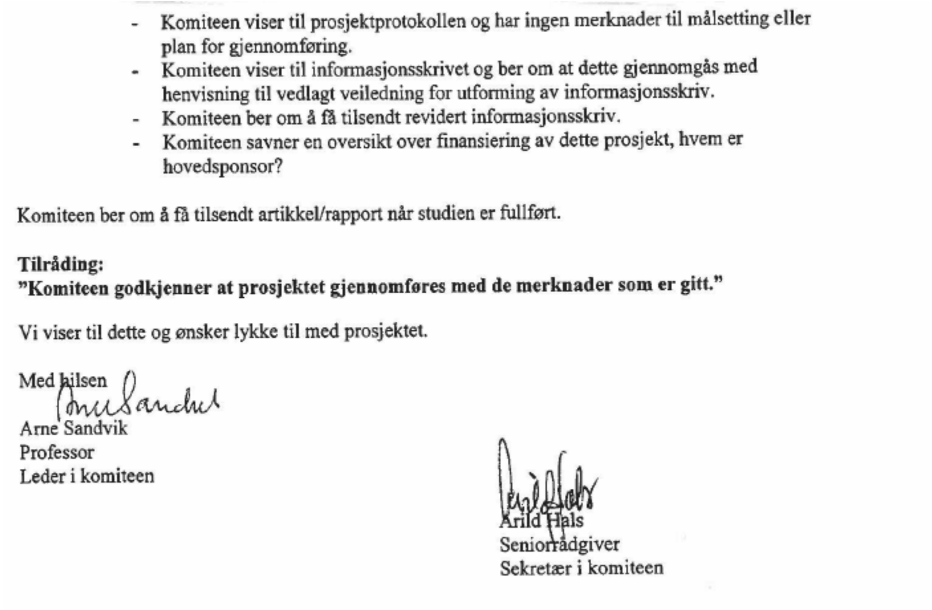
Komiteen vurderte prosjektet i sitt møte 22. september 2006 med følgende merknader og tilråding:

Komiteen vurderte habiliteten til Greta K. Herje, og hun ble funnet habil.

Det henvises til REK-søknad 4.2006.41 med tilbakemelding fra REK om presisering av bedre sammenheng mellom målsetting, hypoteser og metoder. Prosjektprotokollen er revidert i et slikt omfang at det ikke var tilstrekkelig å benytte endringsskjema. Det sendes derfor ny søknad.

Prosjektet er en aksjonsforskningsstudie der stipendiat både leder og forsker på et utprøvings- og videreutviklingsprosjekt for internettbasert verktøy for "individuell plan" i regi av Helse Midt-Norge RHF og NSEP, NTNU. Hovedproblemstillingen i dette prosjektet blir å undersøke om og på hvilken måte en internettbasert løsning for individuell plan kan bidra til å nå målene vedrørende den lov- og forskriftsmessige målsettingen for individuell plan i helse- og sosialsektoren. Prosjektet vil benytte både kvalitative og kvantitative metoder. Forskningsmaterialet kommer hovedsakelig fra utprøvings og videreutviklingsprosessen. I tillegg kommer materiale fra en spørreundersøkelse i landets kommuner som skal tjene som basis for hvor generaliserbare utprøvingsgruppene er samt dokumentasjon fra et EU-prosjekt der SamPro inngår som del av en planlagt europeisk pasientportalløsning for kronisk syke pasienter.

Komiteen har følgende merknader til prosjektet:



- Komiteen viser til prosjektprotokollen og har ingen merknader til målsetting eller plan for gjennomføring.
- Komiteen viser til informasjonsskrivet og ber om at dette gjennomgås med henvisning til vedlagt veiledning for utforming av informasjonsskriv.
- Komiteen ber om å få tilsendt revidert informasjonsskriv.
- Komiteen savner en oversikt over finansiering av dette prosjekt, hvem er hovedsponsor?

Komiteen ber om å få tilsendt artikkel/rapport når studien er fullført.

Tilråding:
"Komiteen godkjenner at prosjektet gjennomføres med de merknader som er gitt."

Vi viser til dette og ønsker lykke til med prosjektet.

Med hilsen
Arne Sandvik
Arne Sandvik
Professor
Leder i komiteen

Arild Hals
Seniorrådgiver
Sekretær i komiteen

Appendix 4: letter to participants in study II.

NTNU
Norges teknisk-naturvitenskapelige
Universitet

Det medisinske fakultet
Norsk senter for elektronisk pasientjournal

Til

Sluttbrukere/klienter som deltar i
utprøving og videreutvikling av
IKT-verktøyet Sampro i Trondheim kommune

Vår dato: 01.09.05 Vår ref.: J. Bjerkan Deres dato: Telefon : 73551533

Deltakelse i gjennomføring av PhD-prosjektet: "Bedre med individuell plan på nett?"

Ved oppstart av prosjektet "SamPro " i regi av Helse Midt-Norge RHF ble du orientert om at det også gjennomføres et forskningsprosjekt i tilknytning til dette. Forskningsprosjektet skal forsøke å finne ut hvor stor nytte dere som bruker Sampro, både brukere og hjelpeapparat, har av dataverktøyet i forhold til å benytte en papirbasert versjon. Forskningen utføres i regi av norsk senter for elektronisk pasientjournal, NSEP, ved universitetet i Trondheim, NTNU.

Stipendiat Jorunn Bjerkan er leder for både forskningsprosjektet og videreutviklingsprosjektet. I kommunen din er Jon Ole Hedne kontaktperson. Jorunns bakgrunn er mange års erfaring som sykepleier og sykepleieleder, dessuten med innføring av datasystemer for sykehusene i regionen. Veileder for forskningsprosjektet er professor og kommunelege Anders Grimsmo.

Vi har søkt regional etisk komité og datatilsynet om lov til å gjennomføre forskningsprosjektet. Vi spør også deg om å få lov til å bruke data fra din individuelle plan. Vi vil i tillegg be om å få intervjue deg og ansvarsgruppens medlemmer, samt være til stede i møter som omhandler din plan.

Deltagelse i forskningsarbeidet er frivillig og du kan også reservere deg fra enkelte deler av prosjektet. All informasjon vi innhenter vil være taushetsbelagt og vil bli anonymisert.

Jeg håper på en velvillig mottakelse av denne forespørselen. Øvrige deltakere i ansvarsgruppen vil få egen henvendelse.

Med vennlig hilsen

Jorunn Bjerkan
Stipendiat

Anders Grimsmo (s)
veileder