

3P – Patients and Professionals in Productive Teams - a health service research proposal

Relevance relative to the call for proposals

This proposal answers the call's focus on health service research, quality of care, patient oriented research and patient safety.

The health service faces an ageing population, which is larger, more complex in terms of long-term conditions (LTC) and multi-morbidity, and expects care to be more individualized than previous generations. This scenario threatens the sustainability of health care, as we know it. Our EPITAL partner, has created a truly citizen centric- and e-health supported solution for patients with Chronic Obstructive Pulmonary Disease (COPD), which reduced admissions for patients by 50%. However, positive results from one context are difficult to reproduce(1, 2). There is an urgent need to understand better how to operationalize patient centered, integrated care, leveraged by technology in a way that reproduces results.

Our project includes four pilot sites, which all share the same visions and approaches as EPITAL: using innovative technology to develop care that: 1) is truly citizen centred 2) is coordinated proactive and planned 3) has one-point of contact 4) uses interdisciplinary teams and 5) is a learning care system. The project has a parallel focus on implementation of best practices. The proposed project aims to radically improve quality of care, patient safety and patient orientation for citizens with LTC. The ultimate goal of this project is the triple aim: improved outcomes, improved care experience and reduced costs

Research strategy: Redesign of care is a complex intervention. The active ingredients are multiple, interacting and context-dependent. The research approach takes account of this, by using methods with a long tradition in quality improvement (Plan -Do-Check-Act). Key focus areas for research are: 1) E-support for multidisciplinary teams, 2) The digitized individual stepped care plan 3) Implementation and deployment model 4) The individual patient experience.

Research questions answered in this study:

1. What are the key elements of truly patient centred and integrated care for LTC-patients?
2. What are the effects in our four pilot sites on patient-, clinical-, and organizational- outcomes?
3. Which steps do health managers need to take to implement better care for LTC-patients?

Impact for patients, healthcare and society:

There is a gap between the knowledge base and health care practice. This project will provide decision makers at the local, regional and national level with tools for change: An estimate of the benefits they will reap, the key elements they must design into their care systems, and a “road map” for improvement and maintenance of the intervention.

Aspects relating to the research project

Background and status of knowledge

A rising number of patients with complex- and long-term needs

The following case from the University hospital of Northern Norway (UNN) 2012 illustrates some of the issues this project aims to address: Alfred is a 75 years old widower who lives alone. He has five potentially life-threatening conditions: generalized atherosclerosis with an aortal aneurysm, atrial fibrillation, congestive heart disease, renal failure, and recurrent duodenal ulcers. Alfred's medical record shows that he is a regular out-patient to nephrologist, cardiologist, gastroenterologist, and cardio-vascular specialists. Last year, Alfred had 4 emergency admissions (98 days) to the internal medicine department, all of them characterized by a complex picture of acute and life-threatening cardiac and respiratory failure, with secondary infections. Alfred expresses gratitude for the care he receives, but he is also concerned about his medications. He says, “*I take 20 tablets a day. I don't understand what they are all good for. (...) If I am not careful, 15 or 30 min after I take them, I will either vomit or have diarrhea.*” He estimates that this happens every

second to third day. Alfred's team of physicians have not caught on to this health issue, and are unaware that their carefully monitored and balanced treatments are ineffective about 1/3 of the time(3).

Alfred's story exemplifies a number of system shortcomings towards patients with long-term conditions (LTC). There is no effort to pro-actively prevent the serious clinical deteriorations Alfred is experiencing on a regular basis. Care is fragmented, as the specialists seeing him limit their attention to their area of expertise. Possible disease- or medication-interactions are not reviewed. Alfred repeatedly asks various doctors to review his medications with him, but his wish is not heard. In short, the care Alfred receives is neither tailored to his multi-morbidity nor to his personal preferences, and it is ineffective and costly.

Paradoxically, the very success of our health care system causes the number of patients with multiple LTCs, such as Alfred to be on the rise. Studies of European populations above 75 years of age show LTC-prevalences of more than 70%, and rates of multi-morbidity around 40-50% (4-6). Patients with LTC-conditions accounted for 3/4ths of health care spending in an early US report(7), and patients with 4 or more co-morbidities consumed 5 times as much health services as those with no LTC in a recent Irish report(8). Providing quality care not only for Alfred, but all his peers, all the time, is the task we are facing.

What is best practice?

There are many powerful best practice models of care for patients with complex and long-term needs (9-20). We have singled out the CCM as the most comprehensive model, with both a systems- a clinical- and a patient perspective(17). It has a growing evidence base for its effects on both care-processes, health outcomes(2, 18) and cost-effectiveness(21). The CCM builds on two pillars: "The informed active patient" and "The pro-active prepared health care team", engaging in "productive interactions" for "health and functional outcomes". Both health management support and use of Information and Communication Technology (ICT) are key supporting factors(22). CCM continues to inspire care reforms internationally (23-26). In 2002, on the basis of CCM, the WHO developed the Innovative Care for Chronic Conditions (ICCC) model (27), which differentiates implementation at political level (Macro), the regional (Meso) and the institutional level (Micro). In our Norwegian context, our health authorities are pushing for a large system transformation towards a truly person oriented integrated care model which broadly aligns with CCM principles (28-32). The challenge is: How do we do this?

CCM's strength is also its weakness. Its general and intuitive nature, gives no guidance as to the exact steps of what to do first and last, and in what order, with whom, and how to leverage it with technology. All CCM interventions are interpreted and tailored to the local cultural and regulatory context, which causes heterogeneity of CCM-interventions to be large(2). The active ingredients are remarkably difficult to define(33), positive results from one context are difficult to reproduce(1) and the links between theory and practice are sometimes hard to grasp(2). There is an urgent need to understand better how to operationalize patient centered, integrated care, leveraged by technology in a way that reproduces the results of the best pilot sites in a Scandinavian context.

Why us? A unique Scandinavian opportunity

In three Norwegian health regions (North, South-East, West), and one region in Denmark (EPITAL), there are four pilot projects which have taken to heart the importance of a whole system redesign of care for patients with LTC. The EPITAL project (Denmark) has, by employing both CCM and ICCC concepts, and innovative technology, succeeded in reducing hospital admissions for Chronic Obstructive Pulmonary Disease (COPD) patients by 50% (34). The Stavanger pilot found a before-after effect of 50% reduction in days in hospital(35). Each of these 4 projects has ambitions of up-scaling their services, and all sites have strong ideological, theoretical and technological underpinnings. We share the following "**3P-core ideas**": A vision of a future health care system which:

- Systematically elicits patient needs, values and preferences translated into health goals, and encourage patient involvement

- Creates individual pro-active, stepped care plans, which communicates: goals, self-management, a dynamic health care plan, an action plan for acute episodes and follow-up points
- Has one point of contact for patient's questions and changes in needs, which ...
- ...can respond with a varied set of "clinical response" options, including the recruitment of a seamless inter-professional team.
- Supports continuous learning regarding key outcomes, such as: Patient goal attainment, patient quality of life and health service utilization.

Together these sites represent the perfect opportunity to study the effects of varied contexts, approaches and technological solutions on both process and outcome measures of a visionary whole system-, patient centered-, integrated care- implementation process.

Research questions

The main objective of this project is to achieve the triple aim of improved outcomes, improved care experience, and reduced costs for long-term and complex patients. We must collaboratively draw a road map that takes us from a reactive episodic care system, to a pro-active, goal oriented planned care system. The four pilot sites are linked together in three types of collaboration: A research collaboration, a learning and experience network and a Delphi process (36). We will answer the following main research questions:

- What are the key elements of truly patient centred and integrated care for LTC-patients?
- What are the effects on patient-, clinical- and organizational outcomes?
- Which steps do health managers need to take to implement better care for LTC-patients?

Approaches, hypotheses and choice of methods

Research strategy

In evidence based medicine (EBM), interventions are preferably evaluated in an experimental design. However, the experiment requires exact understanding of the intervention components, how to get it right the first time, and how to keep it stable. The nature of complex interventions requires a different strategy on several levels:

Fluidity of the intervention: Complex interventions have multiple, interacting, and context-dependent active ingredients, which are challenging to identify and keep stable(37). An example: At the micro-level Alfred needs a team of multiple competencies (e.g. a cardiologist, gastro-enterologist, pharmacist and GP), to go through his medication with him. At the meso-level, there must be culture (i.e. skills), -structures (i.e. communication technology) and routines (i.e. how to assemble team) that facilitate a team effort. At the macro-level, the regulatory framework must support information sharing and team behavior. The set-up will be tailored to local resources and priorities. The active ingredient in this picture, can not be isolated to one single thing. The factors act synergistically, to make a new and sustained practice. The most stable component is the theoretical concept of the intervention which includes a description of structures, roles and supporting elements.

Instead of the experiment, we generate knowledge by use of methods which have a long tradition in quality improvement. We integrate the design and evaluation process, in iterative cycles of Plan-Do-Check-Act (PDCA).(38). The theoretical background for such an iterative approach can be found in "complexity theory"(39), and the method is also recommended by Norwegian authorities for quality improvement(31). Generating knowledge is a combination of careful initial planning which pays close attention to the theoretical underpinnings of the intervention, and being willing to test, learn and tweak the intervention as you go along(40, 41). Assumptions and expectations are continuously tested against the empirical results. Each of the pilot sites in this project will function as a "living lab", where the iterative design-evaluation cycles are our empirical data generators. The local sites, will participate in overarching work packages (WPs), and feed experiences and results into these. In the course of the project, we will develop recommendations, which local sites may adopt, test and report back on.

Comparison is another challenge. Although we recognize that randomization is the most robust method of avoiding systematic bias between comparison groups, this method is often out of

reach. Our interventions are directed at the organizational level or geographic site, affecting all patients within the uptake area. Switching back-and-forth between usual care and new care in the same organization is not feasible. Randomizing organizations can be an alternative, but costs often prohibit the number of pilot sites, so that N is too small to make cluster randomization meaningful. This is why, only one of our sites has a control group, while the others have before-after comparisons.

Test-bubble: Because of their complexity, interventions like this often develop in “test bubbles” financed by separate grants to show proof of concept. However, when the grant money dries up, there is not sufficient maturity, buy-in, ownership or adaption to real world constraints to allow for a sustained effort(42). Doing it for real, requires buy-in from management in terms of resource allocation, which is harder and provides less freedom for research based design, but is sustained more often(43). All of the sites included here are developed within a real health care setting, with resource allocation from their local health management. This makes this project especially relevant for further large scale transformation learning.

WP structure: Living labs and overarching WPs

The four pilot projects are organized as separate WPs. In addition each site is responsible for an overarching WP, which will systematically glean experiences from the local sites about the following shared topics: 1) E-support for multidisciplinary teams, 2) The digitized individual stepped care plan 3) Implementation and deployment model 4) The individual patient experience. We use four methods of empirical data collection for overarching WPs: Workshops, Outcomes data, PhD/ post.doc research projects and a Delphi process. All the four overarching WPs will provide the following “**Basic deliverables**”:

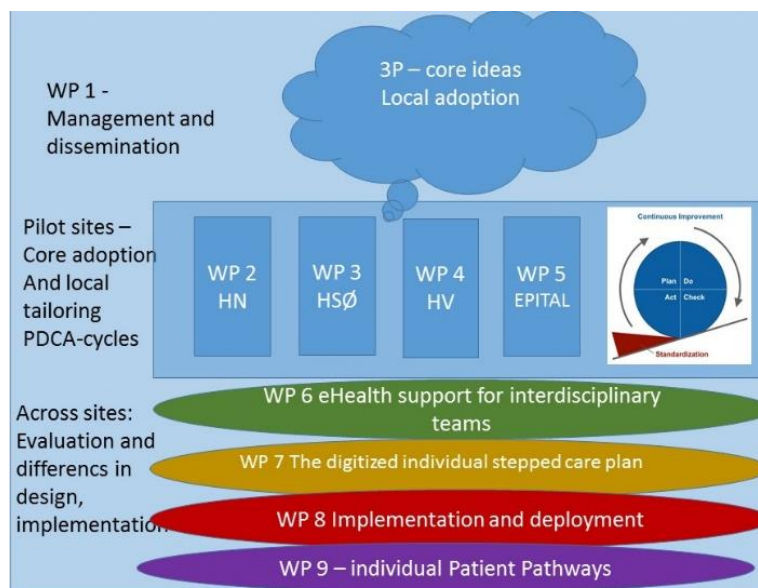
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- A “common outcomes framework” for each WP-topic which is then applied to all sites. These will together form an overall outcomes framework, which will be aligned with other relevant frameworks for evaluation, such as the Model for assessment of telemedicine applications (MAST) and RE-AIM (see below) for implementation(44, 45).
- Outcome reports comparing results of sites and collapsing them into overall effect measures.
- Scientific publications from the dedicated part time post.doc/ researcher on themes within each WP (1 peer reviewed publications per WP)
- A “road map” for health managers on large system transformation of care, which describes the key generic components at a micro- meso- and macro level (Delphi-process).

The post.doc/researcher will apply a mixed methods approach. The research fellow will use the methods best suited to answer the refined research questions. There is awareness in this project of the need for key indicators which are meaningful to the 3P-core vision, and can be aggregated to represent group results.

The project plan, project management, organisation and cooperation

The project is organized with a steering group and nine work packages (WP) divided between the four regions. See figure. Each WP is described below.

Each of our partners in the 3P-project has a wide range of experiences in addition to their pilot, which bring unique competencies to the table: **Epital** has developed a highly successful care model in terms of



reduced need for secondary care. Our project leans heavily on the Epital concepts and their e-health supported care experiences. **The Western region** has experience with general patient portals and low-threshold citizen centric internet services. **The Southern region** has extensive experience in deployment of welfare technology, teams and patient coordinators. **The Northern region** has an experienced host partner (NST), which has the administrative capacity and experience to lead a complex project of this size. NST is a host for the Tromsø Telemedicine Laboratory (TTL - a Center for Research-based Innovation) and has a rich portfolio of regional, national and EU-research and development projects. NST also has a long tradition of developing and implementing person centered technological health systems.

The steering group: The contract between the partners will lay out the mandate for the steering group. The steering group will consist of one representative from each participating region, a representative from the Norwegian health directorate, two representatives from The Norwegian Federation of Organizations of Disabled People (FFO)¹ plus the director for the host partner NST, who is also leader of the board. The steering group makes decisions regarding the allocation of funds, approves budgets, and makes strategic decisions regarding the project, by consensus. If consensus cannot be reached, the group will follow a majority vote (double vote for leader).

WP 1: Management and dissemination

Overall project leader: Professor Gustav Bellika, NST/UNN. The project leader answers to the steering group. WP leaders report to the project leader. The project leader has administrative support from the project coordinator, who runs the day to day administrative sides of the project. The WPs are described below and will be allocated separate budgets and activities.

Lead WP1 dissemination: Senior researcher Gro Berntsen, NST.

We plan: 1) 2 open conferences,. 2) Biannual closed meetings for key personnel to support the overarching WP-activities, co-located with project board meetings. Meetings in the last two years will support the Delphi process of WP 9. Workshop topics will be drawn from WP-leaders suggestions. PhD and post docs will be invited to present their work at these workshops.

Deliverables: Biannual board meetings and workshops. 3 open conferences

WP 2-5: Living lab – pilot sites

WP, Site, WP-lead, Project name, Pilot partner organizations	Target population, description of pilot project activities and e-health support
<p>WP 2: Northern region, Lead Markus Rumpsfeld</p> <p>Patient Centered health care Team (PACT)</p> <p>A board of 6 patient representatives</p> <p>Specialist geriatric services in UNN (Tromsø, Harstad, Narvik) and Nordlandssykehuset (Bodø).</p> <p>Care services in municipalities Tromsø and Harstad.</p>	<p>Population: Frail elderly with recent emergency hospital admission. (N=600)</p> <p>Primary outcome: health related quality of life (MOS SF-36).</p> <p>Interdisciplinary and cross organizational teams</p> <p>Intervention: Person centred needs assessment</p> <p>Integrated individualized stepped care plans</p> <p>A municipal call-centre</p> <p>ICT-tools: Electronic Health Record (EHR) messaging.</p> <p>Comparison: Matched Controls recruited from internal medicine department in Bodø and Narvik (N=600)</p> <p>Future scope: Develop tools to support 3P core ideas in collaboration with WP 5. Implementation of a system of real time collection of health service utilization and patient outcomes from enlisted health service providers (hospitals, GPs and nursing services), using the SNOW surveillance system (see later).</p>

¹ FFO is an umbrella organization with more than 70 member organizations of people with disabilities and chronic diseases.

WP, Site, WP-lead, Project name, Pilot partner organizations	Target population, description of pilot project activities and e-health support
<p>WP 3: South-Eastern Region, Lead: Frode Gallefoss, SSHF.</p> <p>United for health</p> <p>Sørlandet sykehus HF (SSHF), Senter for eHelse og omsorgsteknologi at University of Agder (UiA),</p>	<p>Population: Recently discharged COPD patients, community based COPD patients with increasing instability of the condition. (N=100)</p> <p>Primary outcome: Reduced hospital re-admissions the following year.</p> <p>Intervention: Seamless multidisciplinary teams including the patient, general practitioner (GP), out-reach teams and professional cooperation across organizational borders.</p> <p>ICT-tools: Tablet-PC follow-up with video communication to a telemedical call centre in the municipality a post-discharge telemonitoring program (N=100)</p> <p>Comparison: Before - After- comparison, supported by Statistical process control monitoring.</p> <p>Future Scope: Develop tools to support 3P core ideas in collaboration with WP 5. Implement the telemedical platform in all 30 Agder municipalities within ultimo 2015</p>
<p>WP 4: West, Lead Kenneth Austrått, Administrative coordinator Torbjørn Aarsland</p> <p>Stavanger Univ hospital SINTEF</p>	<p>Population: COPD patients</p> <p>Primary outcome: Health service utilization</p> <p>Intervention: COPD care pathways, organized around patient needs. Symptom monitoring, patient education.</p> <p>ICT-tools: Patient tablet or other mobile device for video communication, Pulse oxymetry or other sensor device, Telemedicine 2-week follow-up of patients after hospital discharge (N=200)</p> <p>Comparison: Before- After design</p> <p>Future scope: Develop tools to support 3P core ideas in collaboration with WP 5. Cloud based ICT solution Provide tools for effective information sharing between service providers. Expand to another diagnosis specific pathway.</p>
<p>WP 5: Denmark, Lead: UNN-HF in collaboration with Klaus Phanareth.</p> <p>Patient panel: Advisory board includes chair of the Danish patient Association of Lung diseases</p> <p>EPITAL Health Lyngby Tårnbekk municipality, Københavns Universitet</p>	<p>Population: Patients/citizens with COPD (GOLD 1-4 and mainly 3-4). N=60</p> <p>Primary outcome: Health care utilization.</p> <p>Intervention: Home medications for exacerbation treatment, empowerment facilities, one point of contact: 24/7 call centre. Via the call centre: accessible and responsive healthcare professionals 24/7 including: 1) E-health medical consultants 2) Certified nurses 3) Outgoing certified nurses to patient homes 4) Nurses and doctors at local acute centre(s)</p> <p>ICT-Tools: A personal e-health navigator with: 1) an individualized dynamic care plan 2) health monitoring functionality 3) video-conference system</p> <p>Comparison: Before - After</p> <p>Future Scope: Export and tailor ECM-tools to support core 3P ideas, in norwegian sites in collaboration with WPs 2-4.</p>

Overarching WPs

WP 6: E-health support for interdisciplinary teams

Lead: South-Eastern region: Rune Fensli, Ph.D., Professor in e-health, University of Agder.

Objective: This WP will gather the collected experience of functionality and organizational use of e-support systems for 3P-care delivery. This WP also evaluates the impact and adaptability of ICT tools, and how these tools affect team function.

E-health tools: A framework will be developed for assessment of e-solutions in all four sites formed by two main components: one core set shared by all 4 partners, and one set tailored to the local context the partner. The shared measures will seek to maximize applicability across partners and transferability to other similar scenarios. The measures will reflect two essential areas of e-health: functionality and usability in the following scenarios: emergency settings, early clinical deterioration, patient at home and stable.

Team work: Team care is a central component in the 3P care vision, and is defined by WHO as "...when multiple health workers provide comprehensive services by working together synergistically along with the patients, their families, carers and communities to deliver highest quality of care across settings" (46). At the practical level teams function most efficiently with shared clinical pathways and a common patient record(46). The health practitioner needs to develop team professionalism for efficient team performance(47). Measures for team performance will be developed in collaboration with professor Bærheim, at Centre for inter-professional work-place learning in Primary Care, University of Bergen.

Deliverables: Basic package of deliverables. + one scientific paper within topic

WP7: The digitized individual stepped care plan

Lead: UNN-HF in collaboration with Epital Lars Kayser, cand.med. PhD, associate professor and Head of study of Health Informatics, Department of Public Health, University of Copenhagen, Denmark.

Objective: to learn from the efforts of the four clinical sites with respect to innovation of digitalized individual care plans. These are mandatory instruments to coordinate activities both between patients and care system, and within the care system. To ensure that care is evidence based, we propose to design standardized single disease pathways, which can be merged to create individual pathways for patients with several co-morbidities. The EBM care plan will then be the basis for a tailored care plan, which takes into account the patients individual needs, values, preferences and care goals. The WP will also contribute to the Delphi process described in WP9

Deliverables: Basic package of deliverables. + one scientific paper within topic

WP 8: Implementation and deployment Model

Lead: Northern region: Hege Andreassen, PhD, senior researcher, Norwegian Center for integrated care and telemedicine, University hospital Northern Norway.

Objective: Support implementation with rapid feed-back cycles, and develop evaluation framework with RE-AIM approach. We will use the RE-AIM model to evaluate implementation in the four pilot sites(45). This framework looks at: *Reaching* the target population, identifying the *Efficacy* of our interventions, *Adoption* of the intervention, looking at organizational target groups and whether the intervention is *implemented* in line with the 3P care vision, and evaluating *Maintenance* of the intervention over time. There are a number of factors associated with implementation results(43). We will especially examine effects of fidelity to the 3P care vision on results. A system for effective rapid-cycle feed-back on central outcomes, such as health service utilization and patient reported outcome measures (PROMs) will support the iterative development phases of the PDCA-cycles. The SNOW system supports secondary use of EHR-data and electronic data collection from patients(48). The SNOW system will be installed in all enlisted hospitals, GP-offices and municipalities and provide real-time outcome measures from these sources. This WP is responsible for the Delphi process.

Deliverables: Basic deliverables. + one scientific paper within topic.

WP 9: The individual patient experience

Lead: Northern region, Deede Gammon, NSE

Objective: develop methodology for assessment of individual patient pathways in terms of individual goal attainment, and experience of care. In the individualized Patient Pathway (iPP), the

individual patient meets a set of specialized professionals, which, if the coordination is right, together will address the patient needs. The patient is the only person who is present in all parts of the iPP. A recent Norwegian report challenges health care to transform iPPs: 1) From reactive to proactive and planned care 2) from diagnosis focused to combined EBM and person centered care 3) from fragmented single disease to coherent team-based care and 4) finally from viewing patients as a passive recipients to supporting the informed active patients' role in their own care. This WP aims to record the individual PP experience of these aspects of care at the four sites.

Deliverables: Basic package of deliverables. + one scientific paper within topic.

WP 10 – Safety assessment of new technologies and organisational designs applied in 3P

Lead: Western region, Geir Sverre Braut, Stavanger Univ Sykehus (SUS).

Objective: The objectives of this work package are to: Develop a general model for safety and risk assessment to be applied on the innovation projects in health care to ensure that possible threats to patient safety are identified before introducing new technologies and organisational designs in clinical practice. Test this model on relevant projects in 3P with the aim to validate the model and to reveal possible risks related to the specific innovation projects.

Deliverables: Basic package of deliverables. + one scientific paper within topic.

Budget

See revised budget in appendix. The three participating Norwegian regions each have separate budgets for two WPs: a living-lab- and an overarching- WP. The Epital group has a special role, as internationally renowned experts on patient centered integrated care leveraged by innovative technology. They have demonstrated effectiveness of their care model and have added central elements to this protocol. Their contribution is essential for the Norwegian project to move forward. Therefore, the host partner UNN-HF has a budget which allows for both local activities in Norway and for subcontracting the expertise of our Danish collaborators.

Key perspectives and compliance with strategic documents

Compliance with strategic documents

The challenges of a fragmented and profession centric care system has been underlined by several policy and strategic documents from top government to regional and hospital trust levels the last five years (28, 30, 31, 49, 50) The intervention outlined here respond to reports which have outlined these challenges in the Norwegian context(3, 51, 52).

Relevance and benefit to society

Expected project benefits for patients (current and future): improved health and function, improved experience of care and improved support for self-management. Benefits for health professionals: improved competency, organizational structure and tools for care of long-term patients. Reduced utilization of secondary care resources, freeing up resources for other activities. Benefits for society: better understanding of success factors for patient centered integrated care interventions for LTC-patients, making the model transportable to other contexts both nationally and internationally.

Environmental impact

E-health services will reduce transportation for health purposes, but may increase electricity usage. No calculations exist, but we anticipate a net reduction in energy consumption.

Ethical perspectives

The studies will be performed in accordance with current regulations and legislations. The necessary approvals for the PhD/post.doc projects will be sought from the Regional Ethics Committee (REK). The interventions included here seek to optimize delivery of care that is already considered best practice, which is why there is no reason to believe the intervention groups runs higher risks of adverse events than the control groups. The interventions will all be registered at ClinicalTrials.gov.

Gender issues (recruitment of women, gender balance and gender perspectives)

The project will pay attention to equality and gender issues in both patient recruitment and gender interactions in analyses. The research team will endeavor to ensure that both genders are represented among staff.

Dissemination and communication of results

Dissemination plan: See electronic form. The project will disseminate the results through international peer-reviewed journals, workshops and open conferences held by the project, and a project web-page.

Communication with users: The research team will be in close collaboration with the patient panels at each pilot site. Patients who engaged in the project will also be invited to workshops. Patient organizations will be invited to open conference events. The public will be informed by press releases, feature articles by involved researchers and health professionals in order to ensure a general commitment in the involved regions and municipalities.

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