A digitally supported person-centered, integrated and proactive care system. What does it look like, and how do we get there? A qualitative study of healthcare system stakeholder perspectives.

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Abstract

Background: In the face of the demographic change, patients, authorities, and professionals express a need to radically reorganize health services for patients with long-term and complex needs (CLNs) to maintain sustainability and quality of care. In line with policy recommendations, the Patients and Professionals in Partnership (3P)-project transition from reactive, single-disase, profession-centric care to digitally supported Person-centered, Integrated, and Proactive (Digi-PIP)-care. In this paper we collected insights from a wide stakeholder group associated with 3P, representing those who use, work for, or shape the Norwegian care system.

Objective: To answer the following research questions:
• What do stakeholders understand by the terms digitally supported, Person-centered, Integrated, and Proactive care?
• How do we transform care towards Digi-PIP care?

Methods: This research was a collaborative effort involving observations and co-creation in 4 Workshops, with 104 stakeholders representing patients, informal caregivers, professionals at all levels of care, healthcare decision-makers, e-health providers, and health service researchers from four innovation hubs in Norway and Denmark. Participants worked in groups, each creating three oral poster presentations of their discussions and insights. A condensed summary of the 45 filmed presentations was the basis for an inductive/deductive content analysis structured by the research questions.

Results: A wide range of healthcare stakeholders recognize Person-centered, Integrated, and Proactive as intuitive, critical and synergistic features of high-quality and sustainable care.

Stakeholders agreed on the essence of the three concepts:
• Person-centered care (PCC) is guided by the patient's answer to the What Matters To You? (WMTY?) question.
• Integrated care recognizes the patient journey as a team product that requires a digital shared information flow.
• Proactive care is key to sustainability. It builds on a prioritized shared care plan, which supports patient involvement and engagement for realistic self-care and "WMTY?"-goals. In addition, proactive care involves the active use of health data, sensors and algorithms to identify opportunities for prevention/ early treatment.

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• Education and training to support professionals in the delivery of person-centered care.
• New organizational roles and logic to reduce care fragmentation.

• A shared digitized information flow to enable all contributors to be aware of personal goals, shared care plans, and risk-reduction strategies.

Conclusions: Stakeholders agreed on what Person-centered, Integrated, and Proactive care is and found these features useful in describing sustainable high-quality patient journeys. Transforming care requires multiple synergistic innovations in education, organization, and digital information systems. There is a need for further research into the regulatory and economic support of such innovation

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A digitally supported person-centered, integrated and proactive care system. What does it look like, and how do we get there? A qualitative study of healthcare system stakeholder perspectives.

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a need for further research into the regulatory and economic support of such innovation.

Keywords :
Patient-centeredness; health-services; co-creation; digitalization; Integrated care; Proactive care.

Introduction

Modern medicine achieves outstanding results and is a huge success. We know more about improving individual and population health than ever. However, as we witness these ongoing improvements, both patients and health professionals repeatedly bring up the following concern: Healthcare is too focused on condition-specific procedures and standards and thereby loses sight of the unique characteristics of both the person and the context of the person who is seeking our help (1-3). The call for Person-centered care (PCC) comes from many different quarters and is far from new. In the late 1800s, Sir William Osler said: "The Good Physician treats the disease; the Great Physician treats the patient with the disease."

Now in the 21st century, strengthening person-centeredness and involvement in health services is widely recognized as a key part of policy-making across national care policies, as well as being encouraged by international bodies such as the World Health Organization (WHO), the European Union (EU), the Agency of Healthcare Research and Quality (AHRQ) and The Institute of Healthcare Improvement (IHI), the latter two from the US (1, 4-6). For example, the WHO encourages integrated and person-centered care to establish services better tailored to people's needs (1). WHO describes people-centered care as:

> *"Empowering and engaging people is about providing the opportunity, skills, and resources that people need to be articulate and empowered users of health services and advocates for a reformed health system. This strategy seeks to unlock community and individual resources for action at all levels."*

However, the gap between PCC rhetoric at the management and policy level and the experiences of patients and professionals at the frontline is large (7-10). Both patients and professionals report that PCC is difficult to deliver in a target-driven culture (7, 11).

For patients with long-term and complex conditions, where health and care by necessity become an integral part of the service user's life, it is clear that excellent technical care is not enough. Care must also fit into the life of the person who needs that care, and only the person has the legitimacy and knowledge of what is meaningful and realistic in the context of their life (12-14). Care for CLNs often involve many different professionals, making care integration part and parcel of person-centeredness, as care organized by person instead of condition, will contribute to less fragmentation, gaps, and duplications of care{de Bruin, 2012 #8895}. Sustainability is thought to hinge on minimizing risks before they become clinical crises, either through prevention or early treatment{Steventon, 2012 #5267}{Kruse, 2023 #15391}. Finally, it is becoming increasingly clear that digital tools are essential to meet the challenges ahead, both to improve care quality, relieve professionals and improve access to care {WHO, 2019 #12343}. The digitally supported, patient-centered, integrated and proactive care journey (Digi-PIP) is an amalgamation of key policy supported features of high quality

sustainable care.

While the policy level has digitally supported PIP-care high on its strategic agenda, there is no clear roadmap for creating such a system (15). The answer lies at the crossroads between theoretical perspectives, empirical evidence from prior implementation efforts, and stakeholders' experiences in the field. The WHO and most healthcare authorities acknowledge the increasingly important role of digital tools in reaching healthcare goals such as Universal Health Coverage (UHC), quality of care, and accessibility to care in the face of increasing population needs and scarcity of professionals (16, 17). We have previously explored the theoretical perspectives and the current empirical evidence for Digi-PIP care (18, 19). In this paper, we seek to learn from the stakeholders that use, work in, or shape the care system in the Norwegian context.

The Norwegian care system compares favorably with most other care systems in terms of outcomes(20), and in the same way, as many other national care systems and international healthcare bodies, it has aimed to transform care towards a Digi-PIP-care, in both legislature and strategic white papers over the last 2 decades (21-23). The Norwegian commitment to apply technology to pursue these goals is tied to similar European ambitions, such as the EHDS, and is outlined in numerous whitepapers (24-27). Thus, the Norwegian context is relevant to the goals and processes shared across international care systems.

The aim of the 3P (Patients and Professionals in Partnership){Berntsen , 2022 #14187}-project is to support change towards: “a digitally supported Patient-centered, Integrated, Proactive (PIP) healthcare service,” which builds on the experiences of four existing innovation hubs. To this end, the 3P project has grown a wide network of stakeholders from all levels of care, including researchers, and provides a perfect basis for the exploration and documentation of stakeholder insights.

Within the 3P context, it was clear that although participants shared a person-centered vision, it was difficult to articulate exactly the common vision. Even more challenging was the formulation of clear strategies that would change frontline care towards the digitally supported PIP vision. With this background, the authors invited a wide group of stakeholders linked to the 3P network to participate in four workshops where the goal was to explore both the vision and strategies to reach the vision.

The research questions we are answering in this article are:
1) What do stakeholders understand by the terms digitally supported Person-centered, integrated, and proactive (PIP) care?
2) How do we change care towards Digi-PIP care?

Methods

This qualitative study is based on video-recorded presentations from four

workshops representing a wide set of Norwegian healthcare stakeholders. The stakeholders included patient representatives, informal caregivers, health professionals, decision-makers from all levels of care, e-health decision-makers, and health service researchers. Our data is a set of filmed poster presentations from the workshops, created in a dynamic process by representatives of patients, professionals, and decision-makers in care.

Relevant theoretical perspectives:

Interactionism

We take an interactionist epistemological point of view ((28-31), where the interpretation and understanding of terminology and concepts depend on the background context and cultures of the participants and the researchers. Participants in the interaction will clarify differences through dialogue, presentation of examples, and questions to produce a common ground for meaningful interactions.

Context of authors and workshops:

The authors are all health service researchers with medical, nursing, socio-anthropological, e-health, and sociology backgrounds. We produce knowledge together with our informants, in the interest of improvement of the health service we study (28). Participation in the workshop was designed to both provide data for research and an opportunity for reflection for the participants. The authors all had experience from previous healthcare improvement/ intervention projects grounded in the theory of PIP- services as described in the introduction and elsewhere (15).

The workshops were set in Norway, a Nordic welfare state where equality is a core value, there is universal coverage of publicly funded healthcare, and the PIP principles have been central to healthcare legislation and policy for the last 20 years. The workshops were held in 2019, just before the global Covid 19 pandemic. At the time, there was a strong public awareness of the challenges that face most healthcare systems worldwide: the demographic changes with a growing elderly population ahead, the importance of the digital information revolution, and the future scarcity of health professionals.

Complex Adaptive Systems (CAS)

The theory of Complex Adaptive Systems inspired the design of the workshops. (CAS), which states that you cannot understand the whole by looking at the sum of the parts. CAS portrays complex systems as a collection of interdependent and self-determined agents. The system behavior is “emergent” and depends on how multiple local agents interpret and act according to their perception of goals, rules, incentives, and culture. (32-35). Healthcare events and processes result from underlying system structures, which are the product of the underpinning mental model. The mental model is “the raison d’etre” for the system, the story that the system owners and agents use to explain why the system exists.

We posit that the current mental model of care is dominated by the episodic, single-condition, reactive bio-medical care model, with psycho-social add-ons in some areas (36) (37). Change of the mental model, will underpin new structures and processes in the areas of funding, organization, legislation, information systems, and education (38). We wanted to capture the voices of a heterogenous group of self-determined agents that contribute to a healthcare system. This was the rationale for the invitation of a wide stakeholder group to discuss and reflect upon the system they are part of, so that insights from the group work would build on the group's collective experience.

Normalization Process Theory:

We were also inspired by the Normalization process theory (NPT) developed by Carl May(39, 40), which posits that change management toward a new normal hinges on the four following stages of 1) Coherence: shared understanding and narrative of change. 2). Cognitive Participation: Strategy for change across the organization, aligned with local values and conditions. 3). Collective Action: Implementation. 4) Reflexive Monitoring: Continuous monitoring to adjust and sustain change.

The workshops aimed to facilitated the first two NPT-stages, fostering a coherent understanding among participants from diverse backgrounds and formulating a strategy for change grounded in a patient story.

Data collection

Population and sample

The 3P project was a meta-project constructed on “top of” four existing individual innovation hubs. In 3P, the four pilot sites pledged to learn from one another and their implementation experiences. Their shared vision was To use innovative technology to develop care that 1) is truly person-centered, 2) is coordinated, proactive, and planned, 3) has a single point of contact for the patient, 4) uses interdisciplinary teams, and 5) is a learning care system (41). Briefly, the four pilot sites can be described as follows:

- Northern Site: Created the Patient-Centered Team (PACT) model to facilitate better care for elderly persons with complex and long-term needs (19).
- The Danish hub EPITALET (Lyngby-Taarbekk) later morphed into PreCare based in Odsherred, a technology-supported person-centered care support system for patients with Chronic Obstructive Pulmonary Disease (COPD) and a commercial e-health enterprise: Epital-Health (42).
- The Western hub: Health@home – Video-supported consultations with COPD patients 14 days after a discharge for a COPD exacerbation (43).
- The Southern hub: Builds on Telma and United4health (44, 45) projects and translates a hospital-based COPD follow-up after discharge into a municipal care follow-up service (46).

- See more about 3P here

3P conducted four "Road-Map to Person-Centered Care" workshops in Narvik, Stavanger, Kristiansand, and Oslo. The first three locations were chosen to engage stakeholders from Norwegian innovation hubs, while Oslo hosted national decision-makers. Due to resource constraints, the Danish site and Central region were not included, but representatives were invited to the Oslo workshop.

Invitations were sent via email and word of mouth, stating: "*Our goal is to create digitally supported, person-centered, integrated, and proactive care*." (See Appendix A for full invitation). We do not have a full overview of all who received an invitation, as invitations were forwarded to relevant persons through personal connections and a snowballing process. A total of 104 participants attended the workshops: Narvik (n=40), Kristiansand (n=19), Stavanger (n=22), and Oslo (n=33). Table 1 provides an overview of participant roles, categorized by their dominant role in the workshop.

ROLE	N	%
Patient or Informal caregiver	10	10%
Clinical Professional	30	29%
Decision maker	45	43%
Researcher	13	13%
Other	6	6%
All	104	100%

Table 1: Distribution of stakeholder roles in 3P-Workshops, Norway 2019

The workshops

We assumed participants were familiar with the terms Digital, Person-centered, Integrated, and Proactive care, but that interpretations could vary according to background. To make the dialogues as tangible as possible, we framed the discussion in the context of the anonymized case story of “Olav,”:

> Olav *is an elderly man with communication and eating difficulties (dysphagia and dysarthria) due to a head injury. He has a mechanical valve (Percutaneous Endoscopic Gastrostomy- PEG) to allow additional fluids to enter directly into his stomach. The home nursing services visit regularly to help with his PEG, but Olav actively distances himself from them.*
>
> *We meet Olav at discharge from a hospitalization for constipation and dehydration, due to poor fluid management, probably secondary to collaboration challenges between Olav and the nursing service. The nursing service now worries that the poor collaboration will recur with new hospitalizations as a result. They question Olavs ability to manage on his own, while Olav is clear: he does not wish to be institutionalized in a*

nursing home.

The case was resolved as "Sonia," a nurse from a multidisciplinary team for complex long-term cases, built trust with Olav and established new transparent and realistic routines with Olav and the home nursing service. (see Appendix B for a more detailed case story).

The participants were asked to frame their input within this story. The workshop participants were guided through the program detailed in Fig. 1.

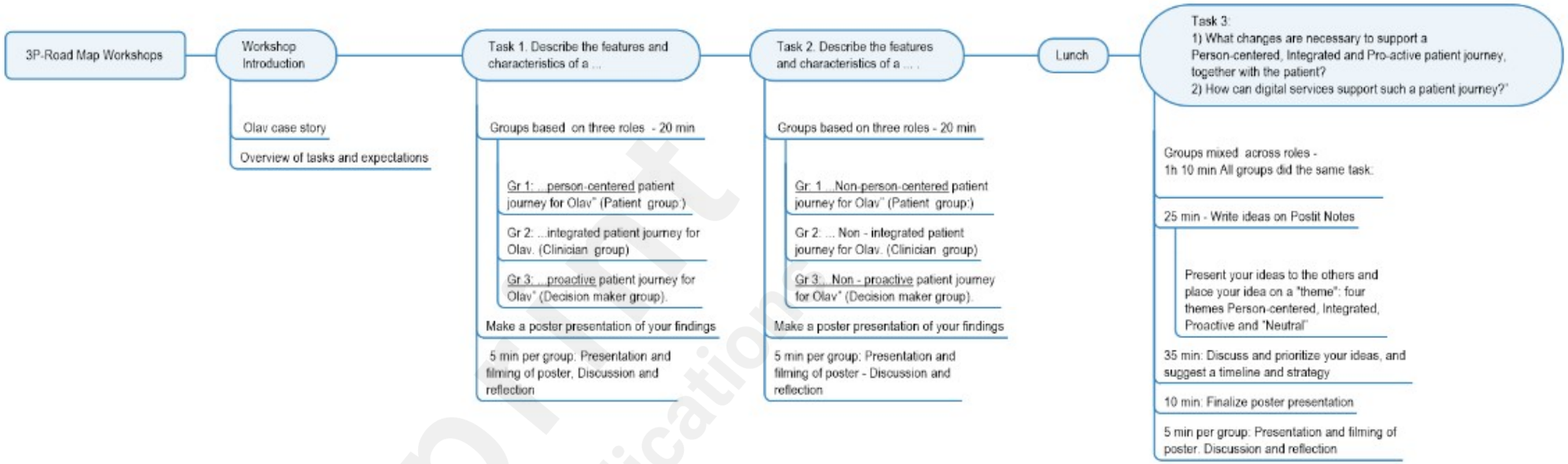

Figure 1: Workshop tasks and flow. 3P-workshops, Norway, 2019.

The first tasks were designed to capture the understanding of the PIP terms. Participants chose a group for the first two tasks according to their self-selected role (Patient, Clinician, or Decision-maker). The patient group described what Olav's care journey would look like if person-centredness was a key feature (task 1) and what would happen if person-centeredness was absent (task 2). The professional group and decision-maker group did the same, except they reflected on the terms “integrated care” and “proactive care,” respectively. Task 3 asked participants for insights on how to transform care towards Digi-PIP in the Norwegian context. Participants were now in new groups that included all roles. In a set of guided steps, the group collected each participant's ideas for change, grouped them, and created a narrative for change.

The groups counted 4-8 people. The main points of the group insights were written up on a poster, which was subsequently presented to the entire workshop by one person in the group.

Analysis

The raw data for analysis included filmed presentations, poster images and workshop log.

Table 2: Analytic approach, Patients and professionals in partnership (3P) project, Norway 2019

Primary analysis	Secondary analysis
Workshop log with reflections among the authors GB, UK, and (L Lindseth) LL. **Video Recordings**: The workshops produced 45 video-recorded poster presentations, each 5-10 minutes long. Inspired by Malterud’s text condensation (47). **Structured condensed summaries** of the film. Preserving essential themes, with relevant ad verbatim quotes and summaries of key points using the following structured template see appendix C.	**Reading of structured summaries**: MG and GB read them with an inductive starting point. The theory of Digi-PIP shone strongly through the material. **Deductive thematic content analysis**, based on Digi-PIP {Tjora, 2018 #12143}. Opinion units were identified, coded, and categorized into various topics that recurred in the data material. We structured results according to the two research questions. We sought to identify recurring and overlapping themes across presentations and the variation in the form of complementary views or disagreements/ conflicts. Our findings are illustrated by quotes from the films.

Ethics and privacy

All participants were informed choosing to participate in and contribute to the workshop was understood as “informed consent.” We prepared participants for

filming of the group presentations and explained how the video and poster material would be the empirical basis for our analyses.

We consider the video presentations to represent a group effort, so no single person is responsible for or can be attached to the opinions presented. Therefore, quotes are not marked with characteristics of the informant, eg gender or profession. No written individual consents were collected, as we collected no data about any identifiable individual.

Results

What is person-centered care?

What matters to you? (WMTY?)

Giving the "WMTY?" question prominence and power in a shared decision-making process was highlighted as the essence of PCC. Finding good answers to the “WMTY?” question can be difficult, especially if the health challenge is novel or overwhelming, or as in Olav's case, there are communication challenges. As circumstances and insights evolve, revisiting these questions is crucial.

While "What Matters" and "Value" are closely related, they are not identical. The primary aim is to restore the patient's previous level of function. If that's not possible, it's essential to understand what outcomes the patient values. After a catastrophic health event, the patient is the only person who can re-define identity, and what a new life might look like. The professional provides knowledge and experience about what is possible. When patients struggle to express their needs, values, and preferences, such as in mental health illness or cognitive impairments, family members are vital in understanding "what matters." Several participants reflected on their understanding of “WMTY” by underlining that:

«A value-based health service creates value for the patient, in the sense that we help the patient create a life of value for themselves. We, as healthcare personnel, add what the patient needs. It must build on mutual trust: "When I (the patient) gain confidence in you, I will tell you what is important to me." It is essential to devote enough time and attention to achieving this level of trust in the relationship.».

“Creating value for the patient is about understanding each other - patient and professional. It is a relationship where we seek to understand what is meaningful and makes sense to the other person. Then we share the information with relevant service providers so that what comes back to the patient from healthcare is recognizable for the patient and links back to the “WMTY?” question.”

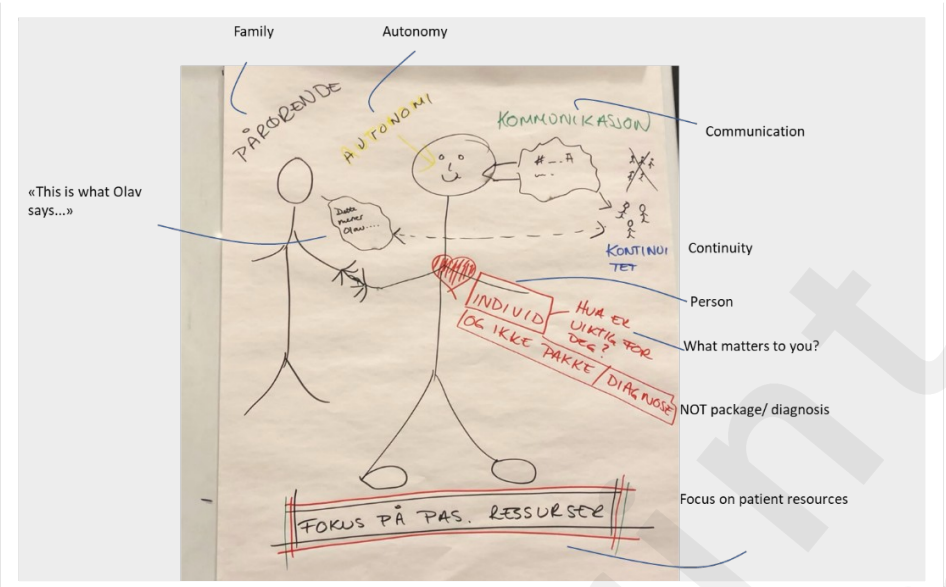

Figure 2. Poster in response to the question: What is person-centered care? From workshops at location C. Norway 3P-road map meeting, 2019.

Prerequisites for PCC

A shared decision-making process based on "what matters" relies on mutual trust and access to relevant information, enabling informed decisions. Trust requires time, familiarity, and understanding of the patient's challenges. Healthcare workers focused solely on diagnoses may overlook threats to a patient's identity. Patients need tailored information about opportunities and risks and time to prioritize.

The healthcare system may unintentionally disempower patients through unequal access to knowledge, use of medical language, and enforcement of unfamiliar healthcare culture and rules. Coupled with the person's inability to assert themselves while they are struggling with mental, physical, and emotional health challenges, the scene can easily deteriorate into mistrust. Situations where trust is eroded create a negative spiral that is toxic, taxing, and disagreeable for the professional and carries a high cost in human and economic terms. One participant stressed the necessity of treating and valuing the patient as a human resource and not simply as a medicalized object:

"Through good communication and building trust with the patient and relatives, a person-centered service should be able to map the patient's strengths and resources. The service should avoid medicalizing the person."

How to implement person-centered care?

System checklists

Several participants mention system support for PCC in the form of a checklist and procedures to ensure that they have asked the patient the “WMTY?” question and that the answers have been documented and brought forward in the care plan.

The person’s focus in focus:

Participants noted the challenge of maintaining a person-centered focus. While professionals acknowledge the need to look beyond diagnoses and respect patients' experiences, they find workflows are set up to prioritize diagnosis and treatment. This can hinder a person-centered approach. Participants emphasized that "the patient is not just a diagnosis or a 'package' to be ushered through a series of transactions."

“It is difficult to see it from the patient's or person's point of view because, as professionals, we automatically take the healthcare professional's role. It is almost impossible for healthcare professionals not to do so. I have been a health professional, and I immediately feel like coming up with solutions. But that is not the task. Our task was to see it from the person's point of view. “

"There was a time when we spent much energy figuring out how to put the patient in the center. Putting the patient in the center reflected a wish to change something. But in a way, we continued to see things from our own (professional) perspective. Each professional had their understanding based on preconceptions about who this person was, seen through the lenses of a physician, a physiotherapist, a nurse...

In recent years, we have learned that there is a big difference between putting the patient in the center and ***taking the patient's perspective».***

Stepping out of the comfort zone

Many participants acknowledged that while healthcare should not take on tasks that are clearly outside the competency of healthcare, we still need to acknowledge non-health challenges when they impact the person’s health. Professionals should consider health issues that may threaten leisure, work, and social roles. Capturing the “WMTY?” and tying the health interventions to it, helps secure patient involvement and engagement crucial to good outcomes. Professionals can also help identify resources, listen empathetically, and validate concerns. Making room for such a holistic approach is an important barrier to PCC, as primary and secondary care workflows are time-constrained and often highly proceduralized. One participant drew the line to Olav’s case saying that:

"This [the care plan] cannot be based on pre-defined procedures. It must be based on some individual analysis of the current opportunities. The approach here must

be a function of the possible options and Olav's thoughts. This is not a goals and results management process. Rather, you need to form an opinion about the next smart move in this dance, which includes both professionals and patients."

Balancing standardized and individually tailored care is a major barrier to PCC.
In the medical domain, the rise of evidence-based medicine, with numerous guidelines for single conditions, is generally considered important for quality of care. Yet, there are no guidelines for specific multi-morbidity patterns. Nor is there any clear advice on how to merge or prioritize multiple guidelines into a coherent individual patient plan.

Tailoring care requires professionals to step outside standardized procedures, which can be daunting due to fear of deviating from guidelines and potential reprisals. Educational systems also focus too little on "health as a resource for life," neglecting the balance between recommended practices and "what matters to you?" This also allows fear of deviating from guidelines to persist. Although participants felt that there is room for tailoring, it requires a certain courage, creativity and personal motivation to shape a plan in line with the patient's focus. Each professional does as best he/she can while also realizing that the bulk of individualization and care coordination may never be addressed. One of many participant quotes that illustrates this:
"At the university level and in education, there is too little focus on "health as a resource for life" or living well with a condition in your everyday life. It is something the students lack. The medical perspective dominates, so there is little focus on the ability to balance the "recommended" way of doing things with "what matters to you?". Most guidelines tell you what to do and what not to do. As a doctor or nurse, you might be chastised for not following the guidelines. There is a fear of deviating from guidelines."

Social and long-term care face similar tensions. The required formal decision process for services lasting > 2 weeks is often mechanistic, standardized check-box processes that elicit standardized care decisions. Because the decision-making is uncoupled from the clinical work, the professionals risk becoming "passive doers of orders" rather than competent professionals who shape care to the needs of the person. This undermines trust, complicates care planning, and favors patients adept at navigating bureaucracy.

"Many make their local routines and systems to construct the "individual plan." (…) Over time, they create procedures that do not involve all [relevant] parties, nor are they grounded in the user's needs. Rather, there is a provider-centric focus concerning the individual plan".

Digital support - Sharing and evaluating "WMTY?"

A fragmented health service threatens the person-centered care journey because the health service has no tradition for informational continuity regarding patient-

defined values and goals.As one of the participants stated*:*

"The goal and expected evaluation points must be explicit in the electronic health record (EHR). This must be accessible to both the person and the professionals because it won't help if only the cross-professional team knows the goal, but the person does not. And, the person's next of kin should also have access to information and dialogue tools."

Building a mutual understanding takes time and requires a new information flow on the topic of patient-defined value across all relevant parties. Without a shared insight into "WMTY?" the resulting service will not be coherent and in line with what was agreed upon. Such inconsistency across providers erodes patient trust, which is the very basis for PCC.

What is Integrated care?

WMTY? guides the care plan

Several informants describe a joint plan developed with the patient, maybe a coordinator, and the wider team as key to integrated care. Building patient trust and engagement is crucial; patients should be involved in selecting their coordinator. Integrated care starts with identifying "WMTY?" which is then translated into numerous professional or diagnosis-specific goals.

The informants said the team should include any person with either a "doer" role and/ or a "know-how" role. The patient is always part of the team, the person who sets the goal, and always has a role in self-management. If desired, next of kin and informal caregivers should also be included. Teams can work sequentially in simple cases, but complex cases require effective communication tools for synchronous and asynchronous interactions. The care plan should integrate the diagnosis-specific guidelines into one person-specific plan, where challenges and activities are prioritized. A coordinator can be beneficial in complex pathways, especially when patients struggle to voice concerns due to mental health or cognitive issues. . Several informants argued the necessity of coordination and information flow:

There is a need for coordinated action between the professionals at the hospital, e.g. the Contact doctor, at the municipality: the general practitioner (GP). An individual plan will be useful, but it must build on holistic thinking that includes all elements: Mind the gap. "What matters to you" may change in different settings. Identify the right level of care. Checklists are a good tool. Avoid fragmentation of responsibility. The collaboration between the parties involved can take place virtually.

"Integrated care is about understanding wishes and needs, building a plan involving the entire team, and bringing in all the competence necessary to meet the goals and needs. Central to this is team and information flow."

"The patient does not care who takes care of what. The crucial point is that it works, that there is a team who does take care of you on your road to healing. We need well-defined roles and tasks: that you know whom to reach out to, who does what on the different legs of the journey."

How to create a seamless and integrated service?

Break down that wall!

Silo-organization not only disrupts information flow, but it also enforces boundaries of "responsibility." When needs arise that are not assigned to a role or a silo, the chain of care may break. While care professionals often go above and beyond to address gaps in care, the system does not necessarily encourage this. As the silo is evaluated by its ability to deliver its silo goals, the leader of the silo will demand that professionals loyally prioritize silo tasks first. Coordination work may have to be done "in secret," in addition to other tasks, without recognition nor remuneration, and might even be punished because it competes with silo goals. Coordination work across organizations is often invisible and unrewarded, leading to a systematic ignorance of existing gaps in the care chain.

A new approach is needed: "Break down that wall!" Silo organization and logic hinder integrated care, as each silo focuses on its own challenges and performance indicators. Several participants highlighted that silo leaders need to be made responsible for the full patient journey, not only their silo services:

We need a new slogan, not the "Patient's health service" but "Break down that wall!"

"Silo organization and silo-logic is a barrier towards integrated care because each silo has enough challenges within its bubble, and they are all too busy already. The managers in the various silos are focused on their "bottom line" – to avoid red numbers and to excel on their performance indicators. As long as this is the case, it is difficult to engage leaders in a shared responsibility across silos. "

The Coordinator

Managing multimorbidity requires integrated care across all conditions, especially when patients face cognitive, mental health, or communication challenges. A coordinator should advocate patient needs and manage information and resources. It is key that he/she has the trust of the patient and can flag needs on behalf of the patient. More importantly, the coordinator also has power across organizations to create a seamless patient journey. Participants underlined the need for the "Sonia"-Coordinator role as exemplified in the Olav story:

"It will vary who should take on the [coordinator] role, depending on the need. Sometimes, it can be the home help; other times, it can be the GP; and other

times, it can be the home nurse. But " Olav " should decide who takes on the coordinator role.»

"We just need a "Sonia" who has a way of acting where proactivity emerges early. Sonja must have extra time and confidence. Every doctor's office and every unit should have a "Sonja" who is an active listener and enables co-creation to see what is possible for the team to achieve together. "Sonja" is a skilled patient journey designer. With her support, the patient can work on figuring out their goal, understand what they need from professionals, and what they can manage on their own.»

Despite recognizing the need for coordinators, participants noted challenges in implementing this role. Since 2001, patients with complex needs have had a legal right to an individualized care plan (IP) led by a coordinator (48). However, resistance and barriers persist.

"There are many examples of coordination needs, which by law include an individual plan and a coordinator. We talk a lot about it. But the individual plan doesn't work in practice. That is the question. Why doesn't it? Perhaps something about management buy-in and implementation needs a stronger focus?"

Some informants suggest that coordination should be a specialized task requiring training and formal authority to overcome silo-leader resistance.

Informal caregivers

Informal caregivers expressed concerns about being excluded from discussions on redesigning care. The following quote by a caregiver state this quite cleary:

> *I am shocked at how little attention there is on informal caregivers when we know they provide just as much care as public services do. We are not invited to the arenas where care coordination is discussed on a system level. Even in this project, you can not improve coordination if you do not collaborate with those closest to the patient, with those whom you expect to provide as much care as the public services do. If the most important stakeholder is missing, coordination will never be perfect.*

The caregivers interests are often assumed to align with the patient's. However, this is a flawed presumption, as the following quote shows:

> *I am an informal caregiver, and I have never been a patient. I don't know what it's like to be a patient. But the patient to whom I am a caregiver knows nothing about what it is like to be a caregiver. The users own 90% of the arenas. Barely 10% of the cases invite the "informal caregiver." We have different interests from time to time. It is important to bring out the next of kin's interests. We have a democratic right to say what we want and don't want... I have no arena to say that. I am always encouraged to put*

> *the user first. I am keen to separate the voices. Analyze the next of kin's voice, but that is not done today. The next of kin becomes one with the user".*

As we see, informal caregivers also have their own agendas. In addition to a need for support in terms of education and relief as caregivers, they also have a right to be recognized and respected as having their own life goals. As huge contributors to care, their needs must be recognized in such a way that they can be resilient and may continue to have a positive role in the patient's life and care. Yet, informal caregivers' needs, values, and preferences are rarely included in care plans, risking inefficient collaboration and burnout.

Digital support – shared care plan and communications

Workshop participants unanimously called for seamless *digital* information flow along the patient journey. An updated plan should start with sub-goals based on "what matters" to the patient, with activities linked to these goals. Digital evaluation by patients and professionals is needed to connect goals with outcomes. Education, training, and ICT support for patients and professionals are necessary for ICT advantages to be fully realized. Paper plans are inadequate tools for the coordination of cross-organizational activities, as these quotes illustrate:

"The individualized care plan bridges the gaps between the agents, but everyone must have access to it to fulfill its role. The digital plan has some features that a paper plan does not have; it is interactive, everyone can access it across time and space, and it can be kept updated."

A shared understanding of the situation is necessary across contributors, in order to fully take advantage of a digital care plan. Thus, patients and their significant others should have equal access , supplemented by synchronous or asynchronous communication, e.g., video conferencing, as needed as this creative vison from one of the groups shows:

«We envision a system "Avatar» which allows everyone to share the same picture. A shared representation of the patient's health conditions. Built upon the sensors that the patient has. It should be visualized in the shared digital care plan. We hope it will materialize soon…"

However, some informants noted limitations of electronic information, which can be overly structured. Complex cases often require nuanced communication best achieved through phone calls rather than standardized digital messages.

"Now, with the standardized electronic messages, we lose something. We "lose many nuances in the language when we only communicate electronically." Much is left out in the electronic messages, making cooperation difficult. It is important to be able to choose suitable communication tools as needed."

What is proactive care?

Proactive sustainable care supports WMTY?

Proactive care, including primary, secondary, tertiary prevention and early treatment, serves to provide care at the earliest and cheapest care level. Almost always, pro-active care, relies on an engaged patient who is good at making the right healthy choices to avert or mitigate clinical crises and need for higher level care. However, the person has the power to veto anything professionals might suggest, which is why a clear link between care-plans and “what matters” to the person, is a critical success factor in pro-active and sustainable care. All risk reduction strategies: such as a shared risk image, monitoring schemes, alarm trigger levels, and realistic alarm plans, should first be aligned with “what matters”. Identifying strengths is as important as identifying risks. This includes the patient's skills and motivation to manage health risks through a healthy lifestyle and self-management. This informant explains it clearly:
"… to be proactive is to start by recognizing the patient’s goals and challenges. You have to find a starting point to engage the patient, to find out what they wish – what matters to them. One must build up the services focusing on self-management, prevention, and co-creation across all involved parties ».

How to move from reactive to proactive care

Ccreating a shared risk image

Proactive services require that the entire team, including the patient, keenly understand potential risks, hereafter called the “risk image.” However, the shared understanding is challenging to develop in a time-constrained context, where professionals work in sequential workflows with few tools to behave as a team. To be truly proactive, we need innovative ways of creating shared understandings. It involves a shared information flow and tools that outline the most important risks. Several informants pointed to the Bow-tie model as a useful tool to build the “risk image” (49, 50).

“…there is a need for a shared opinion across the actors. You could start with, for example, these risk-identification models, pointing to the bow-tie- model on the poster) so that you have a way of building an agreement: this is where we want to focus. We ensure a shared understanding of the goal. So that the different service providers know what their local goals are and that they know what to do

The strongest threats should be assigned roles and tasks so that there is a concrete plan and a structured process to prevent clinical crises and poor outcomes. However, proactive care will fall apart if the different team members react to these threats in different ways. The shared care plan is seen as key to creating a unified and predictable approach to the patient:

“Several underutilized models and tools exist - e.g., joint training and simulation.

One way to ensure continuity around Olav is to limit the number of people who have contact with him. But when that is not possible, we can at least find ways to make people have some common perceptions that make them behave more or less the same when they meet Olav at least. It provides predictability in the approach. The ambulance service does it - there is no reason why the home service should be unable to do the same."

Prioritizing the most important challenges

Patients with CLNs have a whole host of diagnoses. With each diagnosis there is a guideline and potentially useful treatments and self-care measures. However, both the patient and the system is quite often overwhelmed. The participants highlighted made a case for a prioritization of the most important challenges:

«One has to make a joint professional and person-centered argument for prioritization. The Patient and User Rights Act states that patients have the right to make an informed choice among available diagnosis and treatment options. That means you must outline "good practice" to the patient and discuss the options in light of his/her preferences. Which measures are not so important, and which interventions are of high value?

In fact, a care plan with too many points may be harmful. If everything is equally important, then valuable measures may be lost as this quote shows:
"Looking at current care plans in municipal nursing services and specialist healthcare, you will find an unprioritized jumble of good intentions and recommendations. No one has tidied the mess and written up that these "four measures" are most important; these 4 points must be followed closely. A man like Olav does not need a care plan with 22 points. He needs a care plan summarizing the 4 most important follow-up points».

Call 114 - remote follow-up

Patients with LCNs and reduced resilience, will easily loose out on proactive management if there are unnecessary delays. Due to cognitive and morbidity burden, the LCN patient has less capacity for system navigation. The system lacks a "priority access lane" for the most vulnerable patients, leaving them to deteriorate while waiting for evaluation in the emergency department. If assessment is delayed until a full-blown emergency has developed, the damage may be irreversible and the cost of treatment high in both human and economic terms.

Informants suggested a "sub-acute emergency service," e.g., a 911-equivalent telephone service, which serves as a low-threshold remote follow-up service to selected patients with high-risk preventable challenges. Typical users would be COPD patients, patients on chemotherapy, psychiatry patients experiencing trigger situations, etc. Members should have a proactive care plan to be effective, which can be initiated in case of alarming sensor or self-report data. The service

should be able to fluidly and proactively address any challenges that may arise as described in this quote:

“We need an organizational structure where the service can contact the person when, for example, measurements (at home) fall below a given level (for example, a virtual alarm center – call 114). Then, early interventions can be made while the patient is at home instead of waiting for the patient to end up in the hospital.”

Risk of medicalization

While early intervention is often useful, the proactive services also have the potential to medicalize. This is the process of overwhelming life with risks and health concerns. If health monitoring and preventive measures get in the way of life itself, we may have gained life years but lost quality of life. More interventions are not always better. This quote underlines the need to evaluate each intervention in terms of benefits, no-effect, and even side-effects:

"My medical background has taught me that you should discontinue a drug that does not have the expected effect. It is discontinued. But look at other healthcare measures that we expose patients to. Often there is no upfront thought to assessment, and discontinuation. If it does not work, we often add more, based on a belief that it is a question of increasing the “dosage.” In other words, (we need) a kind of awareness of the limitations of non-pharmacological measures. These thoughts may be useful in the process - the evaluation mindset ».

Digital support – high-risk algorithms

Currently, tools to identify high-risk patients for proactive care are not systematically used. Using sensor and self-reported data with algorithms can identify high-risk trajectories, improving outcomes through stronger support and follow-up. Remote follow-up has been tested and should be part of standard care.

"There should be a power within our systems that supports healthcare self-activation. Only then can we be proactive. (...) We should make a net, a digital net, that can capture the “big fish,” e.g., our high-need-high-cost patients, as NN calls them. The big fish are caught in this net. Then someone needs to oversee the net to reel in the “big fish” and initiate the necessary actions to understand the alarm and reduce risk. That is self-activated healthcare.”

The risk-mitigation plan often includes a set of symptom and risk-monitoring activities. Ideally, information technology can substitute humans so that risk data alarms and decision support are automatic, with as little effort and disruption for patients and professionals as possible.

“…digital resources and disease-specific sensors should be part of the picture. They (sensor data) can follow the development and assess the risk. See if what happens is what is expected. If it seems ok.»

Discussion

Principal results

In four workshops, a broad group of stakeholders discussed and reflected on "*a digitally supported, Person-centered, Integrated and Proactive (PIP) care* system." Participants discovered a surprisingly strong agreement across professions, organizations and roles on the essence of the three terms. There was also a shared understanding of the three elements as synergistic and interdependent, meaning they must be pursued together, not one at a time. Sustainable care, relies heavily on the proactive component, but this component cannot be pursued in isolation. The project recognized that informal caregivers are systematically underrepresented in the healthcare improvement conversation, including in our project. The essence of the three terms are:

Table 3: The essence of Person-centered care, Integrated care and Proactive care. Results from the Patients and professionals in partnership (3P) project, Norway 2019

PCC	**Integrated** care	**Proactive** care
was pragmatically defined as ensuring that the patient's answer to the "What matters to you?" question defines and directs the patient's pathway in an ongoing shared decision-making process over time. Prerequisites for PCC are trust, access to relevant health information, and a mutual exploration of patient strengths and healthcare options.	is a team of the patient, sometimes a coordinator/ navigator, and the relevant professionals who create and deliver an individualized care plan that supports "what matters" to the person. The integrated care plan outlines who does what when across roles, professions, and organizations.	is when the team creates a combined self-management and professional support plan to minimize threats and maximize support for "what matters" to the person. Prerequisites are a shared risk image and prioritization of issues across all team members, an alarm, and a contingency plan for when the alarm is triggered. As part of the alarm management plan, a low-threshold healthcare access point (e.g., dial 114) for the most vulnerable patients. Digital sensors and health service data should be used to identify high-risk patients and situations.

What should change to make Digi-PIP care the norm was less unanimous and reflected the informants' wide range of experiences and competencies. However, the suggested changes painted various complementary and mutually supporting ideas. Key areas of change were:

Table 4: Key areas of system innovation. Patients and professionals in partnership (3P) project, Norway 2019

Changes in professional behaviors through	• Encourage professionals to make the person's focus their focus. • Support professionals to go beyond guidelines to tailor care. • Involve Informal caregivers as persons in their own right. They are not an appendage to the patient.

education and raising awareness:	• Establish a shared and prioritized “risk image” of preventable risks. • In case of risk monitoring, which is meant to trigger early treatment, communicate clearly why and how so that lay contributors can follow up • Beware of potential medicalization – interventions should not disrupt the person’s life. Discontinue interventions that do not have the intended effect.
Organizational changes, through change of roles or new roles:	• Make silo leaders responsible for the coordination of the patient journey. Responsibility does not stop at the silo border. • Establish a specialized coordinator role with a mandate to direct resources outside their organization in service of seamless care. • Beware of unmet needs, especially in patients with communication, mental, cognitive, or morbidity overload challenges. A “coordinator” speaks on behalf of the patient to ensure the patient's voice is heard. • Establish a “membership-based fast lane” for patients with unstable and complex long-term conditions where early treatment makes a difference.
Desired digital support:	• The patient’s needs, values, and preferences should be systematically documented and shared across the patient journey. • A shared EHR and care plan across the patient journey. • Digitally shared regular evaluation of patient journey to adjust care to patient goals. • (A)Synchronous communication solutions to the “patient” team • Remote sensor-based digital follow-up with monitoring, defined alarms, and plans for timely early treatment • Use population data to identify high-need and high-risk individuals and offer “membership” to “fast lane” and strengthened services.

There were few suggestions for changes in regulatory or economic structures, which reflects that we lacked participants with this competency.

Strengths and limitations:

This qualitative study is based on input from over 100 informants, with a wide range of stakeholder perspectives: patients, decision-makers, clinicians from different organizations and specialties and professions, health bureaucrats, researchers, informal caregivers, and patient organizations at four different geographic locations within Norway. This is a strength.

Even so, our recruitment of informants had some weaknesses. The attendees were likely to underrepresent stakeholders who disagreed or were indifferent to the Digi-PIP theoretical model. Also, we lacked representation of health sociologists, lawyers, and economists, so important perspectives may be missing from our material.

We claim saturation for the first research questions, as all four workshops gave similar descriptions of Digi-PIP care. We cannot claim saturation for the second research question: interventions to transform care. However, our stakeholders provided a partly overlapping and partly complementary output that paints a broad, coherent picture of challenges and possible points for intervention, which is a strength.

Stakeholders were heterogeneous, yet were eager to discuss with one another and expressed surprise at how similarly they viewed the care system. Importantly, no

group outputs contradicted each other. An important gap in our work was identified by the Informal Caregiver Alliance (Pårørende alliansen) who found that their role was only weakly understood by our team, which was a valuable input to our work.

We found that the NPT framework was a good fit for the workshop (39, 40). We believe grounding the discussion in a concrete patient story was essential for effective communication across professional backgrounds.

A group process can be influenced by strong/dominating personalities who “push” their agenda, or the opposite, shy persons uncomfortable in a group might not be heard. The saturation, comprehensiveness, and coherence of the bigger picture indicate that the workshops' outputs are robust presentations of stakeholder responses to the two research questions.

Comparison with prior work

How our findings either expand, confirm, or refute the theory that pertains to our research questions is relevant to the generalizability of our findings (28). The Digi-PIP, CAS, and NPT frameworks are relevant in our case.

Understanding Digi-PIP care.

Various authors have extensively defined person-centered, integrated, and proactive care. While a full literature review is beyond this discussion, key points are highlighted. Reviews often merge high-level care characteristics from all three terms when describing each term alone. For example, Eklund identified important concepts for patient-centered care: empathy, respect, engagement, relationship, communication, shared decision-making, holistic focus, individualized focus, and coordinated care (51).

When we tasked the participants to describe each of the three terms in the light of Olav’s case story, the participants would do the same as Eklund does: they would include a description of the primary term and topics from the two other PIP elements. For instance, the definition of Integrated care started with a statement that, first, we need to know what matters to Olav, i.e., the essence of PCC. Only then can we create integrated care, a team with complementary skills, working with Olav toward Olav’s goals. This underlines synergies and interdependencies between the three concepts, and pursuing one without the others seems meaningless. However, it also raises an important question: Are the three concepts overlapping, or are we muddling each concept with elements of the other concepts?

We want to argue that the three terms are not overlapping, but because they are so interdependent, it seems necessary to bring the other terms into play because you cannot have one without the other. The overlapping definitions arise repeatedly due to an implicit understanding of the underlying interdependencies. However, it is more useful to understand the essence of each term separate from the others.

Clarity for each term contributes to understanding how these are synergistic and how a comprehensive care system that builds on all three elements can be built. Hence, although all three terms are interdependent, each has its essence, which clarifies our pursuit of Digi-PIP care.

Implications for research and practice

New mental model based on PCC

There is a strong call for a more person-centered service and a focus on the entire patient pathway. Two concrete suggestions are strengthening PCC perspectives in education and enhancing the patient's voice in care plans. This suggests a need for a new mental model incorporating these concepts. Creating a seamless person-centered service requires constructing the patient journey as a tangible entity, not just a mental journey that only exists in the patient's mind. Developing an information unit to describe the patient journey across care units is the first step in classifying, organizing, evaluating, funding, and educating about patient pathways. It is high time we started constructing the patient pathway as a fundamental care delivery unit.

Changing the structure – digitization is important.

There was a clear understanding that siloed and fragmented care organization, was an important structural barrier. Proposals included improving information flow between organizations, changing education to foster collaboration toward patient goals, and introducing new roles to overcome fragmentation. Digital solutions are crucial for promoting the patient's voice and using data for early intervention.

However, changes to regulations, KPIs, or funding rules were notably absent. Some participants felt that focusing on person-centered goals over condition-specific ones seemed too ambitious or unrealistic, given the success of the current disease model. The ideological basis for PCC is already woven into legislation, policy and strategy, and yet, there is a hesitation to make it count at all levels of governance and regulation of our health services.

Living labs to test structural changes

No acknowledged “quick” fixes are available, and in a CAS, there is always the risk that a well-intended change might have unforeseen negative consequences. We have no “magic bullet” either, but we think it is worthwhile creating more “trial and error” experiments that can develop and test structural change to provide answers as to how this impacts the care process and patient outcomes. To make a ” CAS laboratory” would require the intentional development of a “living lab,” where changes can be evaluated as one goes along in a combination of formative and summative evaluations(52). Such an initiative would need active management from the local to national level authorities regarding the

experimental conditions.

Proceduralization and New Public Management (NPM)

NPM has influenced the public sector, emphasizing market orientation and cost-efficient goal-monitoring through KPIs. While appealing, KPIs can lead to poor performance in unmonitored areas (53). Also, constructing KPIs that capture the essence of high-quality care is, as Donabedian described it, notoriously elusive because the concept of quality is itself a construct that changes radically with time, place, and context(54), and key performance indicators that reflect Digi-PIP care are difficult to find (55). Thus, KPIs can never be the main governance approach.

High-quality care can be achieved by applying procedures and standards linked to better outcomes or best practices. In medicine, Evidence-Based Medicine (EBM) has led to numerous guidelines. However, guidelines often fail to address the needs of multi-morbid patients and can cause harm if followed rigidly (14).

There is a case for a guideline for when to follow guidelines and when to build personalized pathways by a common-sense heuristic merging and tailoring of guidelines to the unique person. The latter requires our professionals to be competent and willing to move ahead with the patient in a cautious trial-and-error approach. This can only happen if we infuse our professionals with trust, competency, shared responsibility, and the necessary tools to communicate, learn, and adjust as they go along.

Conclusion

The stakeholders had a clear and unanimous understanding of the essence of the three concepts:

- PCC is guided by the patient's answer to the "WMTY?" question.
- Integrated care: Acknowledges the care team involved in the patient journey. With digital tools, the team plans and delivers care that meets WMTY?-goals.
- Proactive care: Is key to sustainability. A prioritized shared care plan. Support for patient involvement and engagement for realistic self-care to support WMTY? In addition, supportive monitoring of risk, with triggers and alarm plans.

The PIP elements are understood as synergetic and interdependent and must be pursued simultaneously to fully reap their benefits.

The stakeholders suggested a wide range of innovations to support Digi-PIP care:

- Education and training to support new professional behaviors so that professionals are better able to provide Digi-PIP care
- Organizational changes of roles and responsibilities and suggestions for a

few new roles, all to overcome the fragmentation of care.
- Shared information flows to support a common overview of the patient's needs, values, and preferences, the shared risk and care plan, and the use of algorithms at the personal and population level to identify opportunities for early intervention.
- There were fewer suggestions of a legal or economic nature.

In conclusion, the three concepts of Person-centered, Integrated, and Proactive (PIP)-care made sense as a basis for a cross-disciplinary discussion of care improvement, sustainability, and digital health innovations.

Contributions:

GB, UK, and LL designed the workshop program. GB, UK, and LL attended 4, 2, and 3 meetings, respectively. GB led all four meetings. UK and LL filmed the presentations and facilitated the meeting process. GB, UK, and LL reviewed and summarized the films. MK and GB made the secondary analysis's text condensation and thematic coding. All authors have contributed substantially to the conception and design of the paper, critically read and revised the paper, approved the final version, and agree to be accountable for all aspects of the paper.

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Conflicts of interest

None declared

Abbreviations

Abbreviation	Full term
Digi-PIP	Person-centered, Integrated, and

Abbreviation	Full term
care	Proactive Care
WMTY?	What Matters To You?
PCC	Person-centered Care
WHO	World Health Organization
EU	European Union
AHRQ	Agency for Healthcare Research and Quality
IHI	Institute of Healthcare Improvement
3P	Patients and Professionals in Partnership
EHDS	European Health Data Space
CAS	Complex Adaptive System
NPT	Normalization Process Theory
PACT	PAtient-Centered Care Team
COPD	Chronic Obstructive Pulmonary Disease
ICT	Information and Communication Technology
EHR	Electronic Health Record

Data availability

The films of poster presentations generated in the 3P workshops are not publicly available because presenters can be recognized, and we have promised that participant statements should not be linked back to their authors.

The written summaries of each film analyzed during the current study are not publicly available but are available from the corresponding author upon reasonable request.

References

1. WHO. Framework on integrated, people-centered health services. Report by the Secretariat World Health Organization2016 [1-12]. Available from: Accessed at: http://apps.who.int/gb/ebwha/pdf_files/WHA69/A69_39-en.pdf?ua=1
2. Bisognano M, Schummers D. ESSAY Flipping healthcare: an essay by Maureen Bisognano and Dan Schummers. BMJ [Internet]. 2014 Oct; 349:[g5852 p.].
3. Pichumani GRBA, Cowan P, Kamoga R. Person-Centred care systems - from theory to practice. In: Healthcare I-ISfQi, editor. 2023.

4. Rijken M, Struckmann V, van der Heide I, Hujala A, Barbabella F, van Ginneken E, et al. How to improve care for people with multimorbidity in Europe?: World Health Organization, Regional Office for Europe; 2017.
5. Rich E, D. L, J L, M. P. Coordinating Care for Adults With Complex Care Needs in the Patient-Centered Medical Home: Challenges and Solutions. White Paper (Prepared by Mathematica Policy Research under Contract No. HHSA290200900019I/HHSA29032005T); 2012 [cited AHRQ Publication No. 12-0010-EF.Rockville, MD: Agency for Healthcare Research and Quality. Available from: Archived at: http://www.webcitation.org/73DWky5eg.
6. Sampath B, Rakover J, Baldoza K, Mate K, Lenoci-Edwards J, Barker P. Whole System Quality. A Unified Approach to Building Responsive, Resilient Health Care Systems. IHI White Paper. Boston; 2021.
7. Greenfield G, Ignatowicz AM, Belsi A, Pappas Y, Car J, Majeed A, et al. Wake up, wake up! It's me! It's my life! patient narratives on person-centeredness in the integrated care context: a qualitative study. BMC Health Services Research [Internet]. 2014 Nov 29, 2016; 14. Available from: <Go to ISI>://WOS:000348423900001
http://www.biomedcentral.com/content/pdf/s12913-014-0619-9.pdf.
8. Hansen F, Berntsen GKR, Salamonsen A. “What matters to you?” A longitudinal qualitative study of Norwegian patients’ perspectives on their pathways with colorectal cancer. Int J Qual Stud Health Well-Being. 2018;13(1548240).
9. Afulani PA, Phillips B, Aborigo RA, Moyer C. Person-centred maternity care in low-income and middle-income countries: analysis of data from Kenya, Ghana, and India. The Lancet Global Health. 2019;7(1):e96-e109.
10. Leijten FR, Hoedemakers M, Struckmann V, Kraus M, Cheraghi-Sohi S, Zemplényi A, et al. Defining good health and care from the perspective of persons with multimorbidity: results from a qualitative study of focus groups in eight European countries. BMJ open. 2018;8(8):e021072.
11. Witham G, Haigh C, Foy S. The challenges of health professionals in meeting the needs of vulnerable patients undergoing chemotherapy: a focus group study. Journal of Clinical Nursing. 2014;23(19-20):2844-53.
12. Berntsen GR, Høyem A, Lettrem I, Ruland C, Rumpsfeld M, Gammon DB. A person-centered integrated care quality framework. A qualitative study of patients' evaluation of care in light of chronic care ideals. BMC Health services research 2018(18):1-15.
13. Mason B, Nanton V, Epiphaniou E, Murray SA, Donaldson A, Shipman C, et al. 'My body's falling apart.' Understanding the experiences of patients with advanced multimorbidity to improve care: Serial interviews with patients and carers. BMJ Supportive and Palliative Care. 2016;6(1):60-5.
14. Weiner SJ, Schwartz A. Contextual errors in medical decision making: overlooked and understudied. Academic Medicine. 2016;91(5):657-62.
15. Berntsen GKR, Strisland F, Malm-Nicolaisen K, Smaradottir B, Fensli R, Røhne M. The evidence base for an ideal care pathway for frail and multi-morbid elderly: A combined scoping review and systematic intervention review. . J Med Internet Res. 2019.

16. WHO. WHO Guideline: recommendations on digital interventions for health system strengthening. 2020.
17. WHO. SEVENTY-FIRST WORLD HEALTH ASSEMBLY WHA71.7, Agenda item 12.4 Digital health. . 2018.
18. Berntsen GKR, Gammon D, Steinsbekk A, Salamonsen A, Foss N, Ruland C, et al. How do we deal with multiple goals for care within an individual patient trajectory? A document content analysis of health service research papers on goals for care. BMJ Open. 2015;5(12):1-8.
19. Berntsen G, Dalbakk M, Hurley JS, Bergmo T, Solbakken B, Spansvoll L, et al. Person-centred, integrated and pro-active care for multi-morbid elderly with advanced care needs: a propensity score-matched controlled trial. BMC Health Serv Res. 2019(19):682.
20. Health Status: Avoidable Mortality => Treatable mortality: Organisation for economic co-operation and development; 2022 [updated 2022-07-23. Available from: https://stats.oecd.org/Index.aspx?DataSetCode=SHA#.
21. Health-ministry-of-Norway. Regulation of habilitation and rehabilitation, individualized plan and coordinator [Forskrift om habilitering og rehabilitering, individuell plan og koordinator] Lovdata.no2011 [Available from: https://lovdata.no/dokument/SF/forskrift/2011-12-16-1256.
22. 1999-07-02 nr 63 Act on Patient rights [LOV 1999-07-02 nr 63: Lov om pasientrettigheter (pasientrettighetsloven).], (2001).
23. Norwegian Ministry of Health, omsorgsdepartementet] Ho. Norwegian Health and Hospital Whitepaper, 2020-2023. [Nasjonal helse-og sykehusplan, 2020-2023] Regjeringen.no2019 [Available from: https://www.regjeringen.no/no/dokumenter/i-korte-trekk-nasjonal-helse--og-sykehusplanny-side/id2462251/sec18?q=.
24. E-helsestrategi og handlingsplan 2017-2020. Direktoratet for e-helse; 2016.
25. Helse_Nord_RHF. Et digitalt 2038. Digital strategi for Helse Nord RHF 2023–2038. 2023.
26. The digital Norway of the future. National whitepaper on digitalization 2024-2030. [Fremtidens digitale Norge. Nasjonal digitaliseringsstrategi 2024–2030]. 2024.
27. Regulation of the European parliament and of the council—On the European health data space, (2022).
28. Tjora A. Qualitative Research as Stepwise-Deductive Induction: A Stepwise-Deductive Inductive Approach: Routledge; 2018.
29. Miller J, Glassner B. The "inside" and the "outside": Finding Realities in interviews. Chapter 8. In: Silverman D, editor. Qualitative research Issues of Theory, Method and Practice, 3rd edition. Los Angeles I London I New Delhi | Singapore I Washington DC: Sage; 2010. p. 131-48.
30. Jeon Y-H. The application of grounded theory and symbolic interactionism. Scand J Caring Sci. 2004;18(3):249-56.
31. Atkinson P, Housley W. Interactionism. 2003 2022/07/26. London: SAGE Publications, Ltd. Available from: https://methods.sagepub.com/book/interactionism.

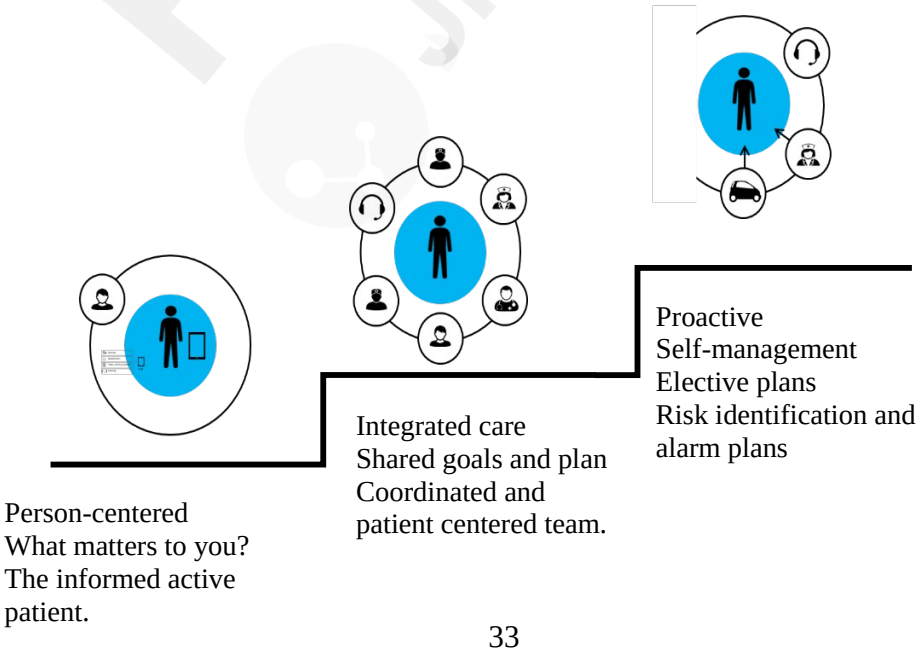
32. Snowden DJ, Boone ME. A leader's framework for decision making. Harv Bus Rev. 2007;85(11):1-9.
33. Braithwaite J, Churruca K, Long JC, Ellis LA, Herkes J. When complexity science meets implementation science: a theoretical and empirical analysis of systems change. BMC Med. 2018;16(1):63.
34. Eide T, Knudsen Gullslett M, Nilsen E, Dugstad JH, Eide H. Tillitsmodellen–hovedpilotering i Oslo kommune 2017-18. Skriftserien fra Universitetet i Sørøst-Norge. 2018.
35. Greenhalgh T, Papoutsi C. Studying complexity in health services research: desperately seeking an overdue paradigm shift. BMC Med. 2018;16:1-6.
36. WHO. People-centred and integrated health services: an overview of the evidence. Interim report. Geneva, Switzerland; 2015.
37. Barry MJ, Edgman-Levitan S. Shared decision making—the pinnacle of patient-centered care. New England Journal of Medicine. 2012;366(9):780-1.
38. Monat JP, Gannon TF. What is systems thinking? A review of selected literature plus recommendations. American Journal of Systems Science. 2015;4(1):11-26.
39. May C, Finch T. Implementing, embedding, and integrating practices: an outline of normalization process theory. Sociology. 2009;43(3):535-54.
40. May C, Finch T, Mair F, Ballini L, Dowrick C, Eccles M, et al. Understanding the implementation of complex interventions in health care: the normalization process model. BMC Health Services Research. 2007;7(1):148.
41. Berntsen G. 3P - Patients and professjonals in partnership [3P - Pasienter og profesjonelle i partnerskap]: Norwegian centre for E-health research; 2022 [Available from: https://ehealthresearch.no/en/projects/3p.
42. Phanareth K, Vingtoft S, Christensen AS, Nielsen JS, Svenstrup J, Berntsen GKR, et al. The Epital Care Model: A New Person-Centered Model of Technology-Enabled Integrated Care for People With Long Term Conditions. JMIR Res Protoc. 2017;6(1):e6.
43. Saleh S, Larsen JP, Bergsåker-Aspøy J, Grundt H. Re-admissions to hospital and patient satisfaction among patients with chronic obstructive pulmonary disease after telemedicine video consultation-a retrospective pilot study. Multidscip Respir Med. 2014;9(1):6.
44. Moe CE, Thygesen E, editors. Recruitment to and dropouts from telemedicine interventions2018: Linköping University Electronic Press.
45. Gerdes M, Gallefoss F, Fensli RW. The EU project “United4Health”: Results and experiences from automatic health status assessment in a Norwegian telemedicine trial system. J Telemed Telecare. 2019;25(1):46-53.
46. Smaradottir B, Fensli RW. The technology use and information flow at a municipal telemedicine service. 2018.
47. Malterud K. Systematic text condensation: A strategy for qualitative analysis. Scandinavian Journal of Public Health. 2012;40(8):795-805.
48. Bjerkan J, Richter M, Grimsmo A, Hellesø R, Brender J. Integrated care in Norway: the state of affairs years after regulation by law. International journal of integrated care. 2011;11.
49. Braut GS, Åbotsvik BF, Dalbakk M, Spansvoll L, Berntsen G. The "Bow-

Tie model" - a method for analysis of risk in clinical work at the interface of specialist and municipal care. [«Sløyfa» – en metode for analyse av risiko i klinisk arbeid i grenseflaten mellom spesialisthelsetjenesten og kommunehelsetjenesten. En egenevaluering av implementeringen i klinisk praksis.] Tidsskrift for omsorgsforskning. 2020;6(2):196-208.
50. Ferdous R, Khan F, Sadiq R, Amyotte P, Veitch B. Analyzing system safety and risks under uncertainty using a bow-tie diagram: An innovative approach. Process Safety and Environmental Protection. 2013;91(1):1-18.
51. Eklund JH, Holmström IK, Kumlin T, Kaminsky E, Skoglund K, Höglander J, et al. “Same same or different?” A review of reviews of person-centered and patient-centered care. Patient Education and Counseling. 2019;102(1):3-11.
52. Greenhalgh T, Russell J. Why do evaluations of eHealth programs fail? An alternative set of guiding principles. PLoS Medicine. 2010;7(11):e1000360.
53. Forbes LJL, Marchand C, Doran T, Peckham S. The role of the Quality and Outcomes Framework in the care of long-term conditions: a systematic review. British Journal of General Practice. 2017;67(664):e775.
54. Donabedian A. The quality of medical care: a concept in search of a definition. Journal of Family Practice. 1979;9(2):277-84.
55. Health Ndo. Norwegian Quality Indicators [Nasjonale Kvalitetsindikatorer]: Helsedirektoratet; [Available from: https://www.helsedirektoratet.no/statistikk/kvalitetsindikatorer.

Appendices

Appendix A - Invitation to workshop participation, English translation

Our goal is to create digitally supported person-centred, integrated and proactive patient pathways for those patients who need healthcare services most.



These are nice concepts, often heard at in sweet speeches, but what do they actually mean to us? Is there a shared understanding of what they mean? Can we give these concepts power and weight?

The 3P project - Patients and Professionals in Partnership - invites you to a roadmap meeting where we seek joint reflection, dialogue and learning about these topics.

During the spring of 2019, 3P organizes five roadmap meetings - one in each region - where we work to understand what person-centered, integrated and proactive care means, and what opportunities these terms provide. The goal is change that will provide better patient-experienced quality, health and cost-benefit ratio.

The target group for the roadmap meetings are the stakeholders in the patient pathway: patients and their informal care-givers, health workers and decision makers in health. Invited participants Only.

3P is led by the National Center for e-Health Research. We work closely with four innovation arenas from north to south: Patient-centred healthcare teams (PSHT) in the north, Helse@hjemme in Stavanger, Telma in Agder and Epitalet in Denmark.

In addition to the roadmap process, 3P has five research areas: Digital support for teams, Individual patient pathway plans, Implementation practices, Patient experiences and Patient safety.

Welcome!

Appendix B - Case story “Olav”

Olav, is an elderly man, with a history of a head injury from a car accident some years back, and had sequelae in the form of a speech impairment and difficulties swallowing food and liquids. Olav cannot speak or communicate in writing. He makes himself understood through signs, and gestures. He organizes his own life, and that of his dog, and does his own shopping. Eating is challenging, which is why, Olav has a “Percutaneous endoscopic gastrostomy (PEG)”, which allows liquid nutrition to be entered into his stomach through a small tube. The home-nursing services were tasked to support his self-management with the PEG, and help him both with medication and nutrition issues, but “Olav” did not much welcome the home-care services attention. He was often gone, or he refused to let them into the house, when they visited. The nurses noted that he had been loosing weight, but were not allowed to weigh him, or to examine him properly. Finally, he was so weak that he had to be admitted to hospital, where he was found to have constipation. When we “meet” Olav” he is about to be discharged from hospital. The home-nursing services are questioning his cognitive abilities, and hence also the wisdom of discharging him to his home, since he seems to need

more care than they can provide. Olav is clear that he does not wish to go to a nursing home.

“Olav was referred to a unit called the “patient centered team” (PACT) which specializes in integrated care for frail multimorbid elderly. The coordinator o “Sonja”, worked on gaining his trust, and then systematically explored how Olav felt about his care. Olav was able to indicate both who he liked working with, and what he found acceptable, through hand-signs and facial expressions. Eating solids was not a problem, but fluids were more challenging. The home care service narrowed down the number of carers who worked with Olav, and they worked hard to gain Olav’s trust. Together with Olav, they made a plan so that it became more predictable who and when the home-nursing service would help him with the PEG. Olav gained weight, and the question of institutionalization was dropped. When the situation was stable, “Sonja” from the PACT team withdrew from the case, so that usual care services were again fully in charge. “

Appendix C - Review sheet for poster presentation films

First analysis of all films – Individual analysis

One analysis sheet per film. All films are reviewed by at least two researchers.
Note info about the film: Name of file, time, place and which workshop task the film is from. Who is doing the analysis. Paste in "poster" images as illustration at the top of the analysis sheet.

Look at the group poster and transcribe the structure or its key-points in first column.

Watch the whole film and note which main topics they talk about. Then - go through the film again and
1) Note the "action" or the story that the presentation conveys - preferably in the same words and terms as the participants.
2) transcribe ad verbatim of illustrative "quotes". Mark the quote with a time-stamp for when the quote occurs in film. If possible, link the descriptions and quotes to the keywords from the poster in first column.

In the third column: Create a concise "Essence" of the presentation that summarizes the message of the film.

Finally - If possible - answer the question: What is the problem represented to be?

Consensus about each film.
The understanding of each presentation may vary by reviewer. To capture differences in understanding between two reveiwers, the two analysis sheets from each film are compared and a final joint analysis is prepared.

Mark with green, text that is perceived as coincident. Mark with yellow - text that is different. Are the differences complementary ? If yes – cut and paste both texts into joint document. If the reivewers disagree – Describe the disagreement and if

possible describe a resolution to it?

The final product is 3 files: 2 individual analyzes and 1 joint analysis. The joint analysis is what is brought into the secondary thematic analysis.

Første analyse av alle filmer – Individuell analyse

Hver for oss.

Noter info om filmen. Navn på fil, tid, sted og WS oppgave i «film skjema». Og hvem det er som analyserer. Max 1 ark per film.

Se på poster og skriv ned struktur fra poster i kolonne 1 (stikkord).

Se gjennom hele filmen – uten å gjøre notater. Skrive ned stikkord – hvilke tema var i fokus her?

Gå gjennom filmen igjen:

- Skrive ut «gode sitater» og markere tidspunkt for de i filmen.
- Skrive ut «handlingen» eller historien som presentasjonen formidler – gjerne med de samme ord og begreper som deltakerne.
- Lime inn «poster» bilder som illustrasjoner.

På nytt skrive ned nye stikkord

Skape en kortfattet «Essens» tekst som sammenfatter budskapet i filmen.

Til slutt – Hvis mulig - svare på spørsmålet: What is the problem represented to be?

Konsensus om hver film.

Formål – å lage en felles beskrivelse for hver film basert på 2 individuelle analyser. Velg en av analysene som «master» og lagre under nytt navn, slik at original beskrivelsene beholdes. Produkt til slutt er 3 filer: 2 individuelle analyser og 1 felles analyse.

Se gjennom de to analysene. Hva er likt og hva er forskjellig? Marker med grønt tekst som oppfattes som sammenfallende. Marker med gult – tekst som er ulik.

Det som er forskjellig – er det komplementært og utfyller hverandre? Hvis ja – klipp og lim begges tekst inn i felles dokument.

Hvis dere er Uenige – klarer dere å bli enige?

Hvis ja – re-formuler slik at det gjenspeiler felles ny forståelse i master dokument.

Hvis nei. Lim inn begge tekster i master, og forsøk å legge til en kommentar om at hva dere er uenige om og hvorfor.

Første analyse av alle filmer – Individuell analyse

Hver for oss.

Noter info om filmen. Navn på fil, tid, sted og WS oppgave i «film skjema». Og hvem det er som analyserer. Max 1 ark per film.

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- Lime inn «poster» bilder som illustrasjoner.

På nytt skrive ned nye stikkord

Skape en kortfattet «Essens» tekst som sammenfatter budskapet i filmen.

Til slutt – Hvis mulig - svare på spørsmålet: What is the problem represented to be?

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