

# Patient Experiences and Digital Involvement in Patient-Centred Care Models

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**Abstract.** The provision of individualised treatment and care from health care services to patients with chronic conditions and multi-morbidities is under pressure because of an increasing elderly population. There is a need for services that are: 1) person-centred, 2) integrated and 3) proactive, and supported by digital technology. The research project 3P- Patients and Professionals in Productive Teams aims to study different patient-centred teamwork models in Norway and Denmark. This paper presents a study on patients' experiences and digital involvement in patient-centred care teams. Qualitative research methods were applied with interviews and demonstrations of technology use made at patient's homes. The results showed that the patients were satisfied with the patient-centred service models and had an increased feeling of safety. A constraint was information sharing between the patient-centred health care team and the patients. Most of them did not have access to read own medical information and mainly verbal information was shared between the patients and the health providers.

**Keywords.** Health technology, patient-centred care, telemedicine, patient safety

## 1. Introduction

There are demographic changes in society with an ageing population that is increasing, and prone to long-term conditions and multi-morbidities [1], [2] and this is threatening the sustainability of the health care systems [3]. Patients, health care professionals and authorities claim the need for re-organising the service model for people with long-term conditions and multi-morbidities. The patient's needs have to be in focus with development of service models that are patient-centred, integrated and proactive [4]. A patient-centred health care builds on a proactive stepped care plan with goals and supports self-management. Digital solutions for communication and collaboration between patients and health providers are a central element in integrated and patient-centred care models. This paper presents a qualitative study about patients' experiences and digital involvement in four health organisations in Norway and Denmark, that apply patient-centred service models. A special focus was made on the use of health technology in home settings. The research questions (RQs) stated were:

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- (1) RQ1: What are the patient experiences with health technology for communication and information sharing with patient-centred health care teams?
- (2) RQ2: What are the benefits and constraints of using health technology seen from a patient perspective?

## 2. Methodology

This paper was made within the research project *3P - Patients and Professionals in Productive Teams* that aims to study health care services models that are run with patient-centred teamwork approaches, but also focusing on digital support for communication and care of patients [5]. The 3P-project is 4-year long (2015-2019) and funded through Helseforsk, a cross-regional health research fund owned by the four Norwegian Regional Hospital Trusts [6]. The project consists of ten work packages that target different aspects of patient-centred teamwork, including patient experiences, patient safety and digital support. Four health care organisations that utilise patient-centred care models and located in different health regions of Norway and Denmark participate in the project. Three of the health organisations provided telemedicine services for chronic obstructive pulmonary disease (COPD) [7][9] and the fourth organisation provided services in the transition period from hospital to home for elderly patients with multimorbidity and chronic conditions [10].

A qualitative research approach was used in this study of patient experiences, with semi-structured interviews and observations of technology use made in the period from June 2017 and until October 2018 [11]. Visits were made to all the four health organisations and the selection and recruitment of informants was made in collaboration with key contact persons. A total of ten informants contributed in the study, whereof two patients from each health region, except for one region where three patients participated. One separate interview was made with a close family member to gather experiences from a family perspective. The informants had the age from 56 to 83, with a mean of 74 years old. The aim of the interviews was to study patients' involvement and experiences from different patient-centred care models and how technology was used for communication and information sharing purposes. The goal was to map the experienced obstacles in the communication and outlining optimal digital support for the patient-centred care models of the future.

Seven of the patients had experience from using health technology at home and made a demonstration of the functions and shared their user experiences. The data collection consisted of audio- and/or video recordings and annotations that were thematically analysed and categorised into three main groups. A total of 7 hours was recorded, and the interviews had a mean duration of 42 minutes. The Norwegian Centre for Research Data approved the study, with project number 53771 [12]. All the informants participated voluntarily and signed a consent form, also the family member.

## 3. Results

The results are presented in three sub-categories: 1) patient involvement, 2) information sharing and 3) patient safety.

### 3.1. Patient involvement

All patients had been or were included to services from patient-centred health care teams that were run with different service models. In two of the health organisations, the patients were enrolled for team services for a limited time. In the other two organisations there was no time limit for the services. In the interviews, patients enrolled in services from all the organisations expressed that they had experienced “increased safety” regarding their contact and medical follow-up from the patient-centred care teams.

Seven of the patients had used a tablet for remote monitoring of COPD and made measurements and questionnaire answers that were sent to telemedicine centres. They all had received a visit at home to be included to telemedicine service and connect the technology. The patients expressed that the service models for telemedicine were well-organised and with pre-defined topics to individually go through, such as inhalation- and breathing techniques. The patients expressed that the telemedicine sessions provided a good opportunity to ask questions and that they learned how to observe own symptoms and self-management. It was experienced as more personal to be able to see the face of the health provider compared to a telephone consultation. The patients used technology from three different vendors, and for all of them it was stated that it was easy to use the equipment and not additional workload in the daily life. It was expressed that the telemedicine nurses were specialised in COPD and could provide more targeted advices compared to the patients’ GPs and the informants would recommend inclusion to such services to other patients.

Two of the patients had received services from a patient-centred team in the transition from hospital to home. They particularly received advices and support related to physical activity and targeted training and had no remote follow up except from telephone calls. They did also receive home nursing services, so they had more than one service provider. One of the patients expressed “*the team cares about me and they try to help me*”.

### 3.2. Information sharing

In both Norway and Denmark there are national health portals for the citizens to access own medical information. In Denmark all the patients had used the national health portal to read own information, but in Norway the patients had neither heard about or used the portal. In two of the Norwegian health organisations, the patients could access their electronic health record at the hospital but not the municipal record. In the two other organisations, the patients had access to own measured telemedicine information in a tablet solution, but no access to information in electronic health records.

In all health organisations, the patients-centred teams had made an individual plan for each of the patients, but only two of the patients had a clear printed plan at home for daily management and how to handle treatment during deterioration.

In one of the health regions, the information about the patients was not shared with other health providers such as the GP or hospital specialist. The patients considered that as a limitation in the information sharing and one expressed: “*it is important that also the home nursing services know about the telemedicine information*”.

### 3.3. Patient safety

The health information about the informants in this study was stored in at least three different information systems: 1) the hospital electronic health record, 2) the municipal electronic health record and 3) the General Practitioner's system. In addition, there were private specialists involved using their own digital system. The use of so many different systems have the constraint of limited interoperability and lack of information sharing, such as the updated medication list of the patient.

Three of the health organisations could not provide written feedback on verbal information given through telemedicine consultations or by use of telephone. One patient expressed *"I write down the instructions immediately"* and another stated that *"this is a limitation because for instance during high fever also elderly people can get confused and forget instructions"*. The patients in one health organisation did have solution that facilitated a message function between the provider and the patient.

The patients in Denmark could use their telemedicine technology also abroad and highlighted the benefit of having a short response time for exacerbations or other acute medical conditions. They expressed that the telemedicine service was most important during exacerbations and did only send measurements in such situations. They also had a "medication kit" always available to reduce the start-up time for treatment.

Regarding information security, none of the patients sending telemedicine measurements were worried about privacy or confidentiality. But most of them had thought that all systems can be hacked, or information sent to wrong receiver. One of them expressed *"it is impossible to avoid sharing of personal information and I trust the system because I can see how useful it is"*. However, one informant stated *"I do not like that companies abroad host and can access our patient data"*.

## 4. Discussion and Conclusion

This paper has presented a study of the experiences and digital involvement of patients enrolled in services from patient-centred health care teams. The research questions (RQs) are answered based on the results.

Regarding RQ1, that asked about the patient experiences with health technology for communication and information sharing purposes. The study showed that the patients expressed an increased feeling of safety and self-management during telemedicine intervention, also seen in [13], [14]. In general, they found the telemedicine equipment easy to use. However, In Denmark, the telemedicine technology shortened the response time and it was possible to use it abroad. Also, in Denmark, the patients were more familiar with using national health portals compared to Norway where none of the patients had logged in to read own information. Regarding the individual plan with goals and "What matters to you?", there should be digital access for patients and where registration of own activities or health-related goals might be a solution.

RQ2 addressed constraints and benefits. There was a lack of written confirmation on verbal information made in telemedicine consultations, a limitation that impacts on the patient safety for instance regarding changes in medication. The patients had limited access to their own information and it was stored in several different systems. When the patient is a "part of the team" s(he) owns the information and should be able to access it in a user-friendly way. Information systems and electronic health records are usually designed for health care professionals and to some degree collaborative work across

organisations, but patients have become a user group of the same systems and their needs must be taken into consideration. Patients that are equipped with tablets for monitoring purposes, should be able to use the same device to access and read all needed information such as an individual treatment plan and medical information in electronic health records.

This study had some limitations such as including a limited number of informants. However, the informants meaningfully represented the patient group with diversity in age, gender and digital literacy, and they contributed with sharing their experiences regarding technology and interactions with patient-centred teams applying different care models. Future work would target a larger comparative study across countries on how to improve the digital involvement of elderly patients.

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