

The Design of Patient Centered Care Pathway

The North-Estonian Medical Center (NEMC) turned to the Innovation Team with a project idea, the aim of which was to make the treatment process of a chronically ill patient smoother and more comprehensive, to find opportunities for earlier detection of the disease and for more effective treatment. NEMC's goal was to adopt a comprehensive and patient-centric view of the treatment journey. The project involved mapping the problems of the whole treatment journey from the patient's point of view, proposing solution ideas and testing them. Suggestions were developed on how to improve the activities of general physicians, specialists, palliative care and other parties who are involved in the patient's journey.

Under the leadership of the Innovation Team, a working group was established, which included representatives of the North-Estonian Medical Center, the Ministry of Social Affairs and the Health Insurance Fund. In the solutions development phase, Tartu University Hospital also joined the working group.

The focus was put on researching the **cancer treatment journey** among the most common cancers types (breast, cervical, skin, lung, colon and prostate cancers). Problems across all cancers as well as type-specific differences were analyzed.

Within mapping the situation, 19 interviews were conducted with cancer patients and their relatives, and one focus group was held with patients only. In addition, interviews were conducted with oncologists, general physicians and specialists of the palliative care department.

Based upon the **synthesis of the obtained information**, three different personas were drawn up, which were not cancer type-specific, but rather described typical patients in terms of their personal characteristics and their need for additional support. Their attitudes, awareness, barriers, and needs were described and typical cancer treatments were visualized. **The main insights from the user research were:**

- **The need for support begins while waiting for a diagnosis.** Most patients indicated that waiting for an accurate diagnosis was one of the most difficult periods of their lives. Doctors also acknowledged that a person needs support starting from the first moment, and that not enough attention is paid to the moment when the diagnosis is delivered to the person.
- **Access to supportive services is random.** When a difficult diagnosis is received, people's lives change radically. They have to re-evaluate many aspects of their lives that people need assistance with (e.g. social worker, psychologist, pastor, pain doctor, etc) – both living arrangements as well as mental aspects. Today, referrals to these specialists depend on the general awareness and commitment of the doctor. It is also not uncommon for doctors themselves to deal with the organizational aspects of patients, which is clearly a waste of doctors' time and energy.
- **Patients are lacking awareness and overview of the treatment journey.** Patients and their relatives want to know what they can do for themselves. Quite often it was mentioned that all the information is owned only by the treating doctor and it did not reach the patients' families. We acknowledged that patients need more empowerment and versatile counselling to cope with their situation.

- **The time and energy required to reach services is enormous.** The doctor cannot book a follow-up visit more than four months in advance. This is a big stress for all patients. Patients and their relatives felt that they had to handle the whole coordination of the treatment journey by themselves, which is a huge systemic barrier for people who are already in a fragile psychological condition.

Following the study, several workshops took place to validate the research results and develop solutions. The work group also paid a visit to Helsinki University Hospital in search for good examples.

As a result of this project, the following **changes to the system** were developed, some of which are being piloted today in three other Estonian hospitals in addition to NEMC, led by the Estonian Health Insurance Fund:

- **Location-specific nurse counselor.** The NEMC introduced a 24-hour open answering machine where people can leave their questions and concerns. Their questions are answered at certain times by a nurse-counselor, acting as a bridge to patients outside the hospital.
- **Location-specific nurse coordinator.** For the patient and their relatives, one person will coordinate the whole treatment journey ("The hospital will have a face"), which will relieve them of the unnecessary additional burden. The nurse coordinator is part of a multidisciplinary treatment team that has a detailed overview of the particular patient's journey. He or she also identifies needs for supportive care and services for rearranging daily life both at local government and national level and acts as a link between various service providers. The nurse coordinator also supports and consults the patient on their treatment journey.
- **Additional visits to various specialists will be added to the treatment plan.** Patients and relatives are empowered to cope with the situation and the side effects of treatment (exercise, nutrition, social, economic well-being and mental health).
- **Measuring patient outcomes and value-based service delivery.** Introduction of patient-reported outcome and experience measurement in the form of a digital solution that would accompany the patient on his or her treatment journey and at the same time provide feedback to medical staff on what is happening to the patient. The goal is to increase patient awareness and adherence to the treatment plan, and to reduce hospitalization and unnecessary referral to the ER.
- **In order to shorten treatment queues** and provide better services to the patient, a digital registry and patient portal (digilugu.ee) are being developed in the Public Sector Innovation Program today.

Several pilots from The Design of Patient Centered Care Pathway project were confirmed and included in the Estonian Health Insurance Funds **stroke management project**, which is currently being carried out in four Estonian hospitals, including the role of nurse coordinator, measuring patient outcomes, and patients' digital counselor with My Patient Journey application.

"As a result of the The Design of Patient Centered Care Pathway, a major change has taken place in the Medical Center and more broadly in Estonian healthcare – we have begun to talk about the patient's journey map as a central tool in service design"

– Siiri Heinaru, NEMC innovation specialist