
CONFERENCE ABSTRACT

Digital presentation of the patient voice in pursuit of person centred, integrated and proactive care

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Severinsen Gro-Hilde¹, Line Silsand¹, Aslak Steinsbekk¹³, Gro Berntsen¹²

1: Norwegian center for e-health research, Tromsø, Norway

2: Arctic University, Tromsø, Norway

3: NTNU - Norwegian university of science and technology, Trondheim, Norway

Background: There is an overall agreement that it is important to shift focus from diagnosis-centric to person-centric care, where patients are active participants in healthcare services they receive. However, to support person-centric care for patients with complex long-term needs, the voice of the person must be present also in the electronic health record (EHR). However, the literature on how to design a digital "person voice" which captures "what matters to you" and presents it in a useful way for healthcare workers, is lacking. The research question is therefore: How can the patients' needs, values and preference be presented in the EHR, in a way that is useful both for patients and healthcare professionals?

Methods: This was a qualitative study where representatives from patient's groups, care-team, vendors, and health authorities have participated in a co-design process. We started with an overview of the presence of the patient voice in today's e-health systems. Data was collected, in the form of notes, and audio-recordings from two workshops where all collaborators participated, ten separate workshops were arranged for sub-groups of collaborators. We also did 1-2 interviews with each of the six patient representatives, transcribed them and used a systematic text condensation method to analyse the material.

Results: The patients wish to make their health and life stories available in the EHR. They wanted to write a brief summary of the key events that have shaped their health and life and that such summary would contribute to: 1) being met as a whole person, and not just a bundle of diseases and 2) not having to repeat their story for each new provider. The patients suggested that: A shared healthcare summary where all healthcare services involved included the main events they focus on, a dialogue box or communication channel aimed to provide the care team with important health-related issues upfront of appointments, and a shared calendar between the patient and the care-team, were also desirable. A prerequisite for the development of the patient voice, is patient access to their EHR across services, and a digital team workspace.

Conclusion: We suggest that development of the patient voice can be supported by the following questions in the EHR to capture the person's needs, values and preferences: 1) what is important for you right now, 2) what matters to you in your life/ health, and 3) what do you want your care team to know about your history? An ongoing dialogue is important to get good answers to these questions in relation to how and when to ask them, and how to follow them up with specific goals and plans.

Future Work: The next step is to test out in an experimental RCT how a digital team tool manages to capture and share the person-centred focus amongst both patients and healthcare workers.