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IMPACT STORIES

NORDeHEALTH

Uppsala University

Digitalization is affecting all of society – everything from online gaming and dating, to banking and even doing tax returns. Healthcare is of course no exception. Today, many countries give patients online access to their electronic health records through patient portals, and this development has a huge impact on patients, family caregivers, and healthcare professionals.

In the NORDeHEALTH research project, we joined forces with an interdisciplinary team of researchers from Sweden, Norway, Finland, and Estonia – countries that all have mature national patient portals – to explore the impact of patients' online record access, and how patient portals can be designed to best meet the needs of different stakeholders. Our research team consisted of researchers from IT, medicine, social science, and humanities, and included patient researchers. This was a necessity to capture all the complexities of this large-scale socio-technical change to healthcare. Carrying out policy analyses, surveys and interviews we made some unexpected discoveries. We found that most of the patient portals were rated highly in terms of ease of use, yet patients were frustrated when information was not accessible – which was often due to regulatory limitations. In some countries, adolescents and guardians lost access to the adolescents' health record for a period of years because of regulations. We also found that every third patient identified a serious error in their online health record, and among mental health patients almost half found errors.

We also found many suggestions to improve these issues – not least by cross-country knowledge exchange. To ensure that our results will actually come to use in this rapidly changing context, we partnered with the developers of the national patient portals and continuously reported our findings to them. We also had close contact with policy makers, healthcare professional organisations, and of course patient organisations. Although the funding for the research project has ended, we continue our collaboration with key stakeholders, with the goal that our research will contribute to eHealth in the future being more useful and accessible for healthcare professionals, family caregivers, and most importantly patients.

"Some of the concrete impacts our project has had so far are; a direct influence on a new Swedish policy proposal for adolescent and parental record access; our research is used as course literature for healthcare professionals in Norway, as input on how to write notes in a record that patients have access to, and results from the project have had a direct influence on the re-design of the Estonian patient portal."

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