

**Titel:** Citizen's use of the national Swedish health portal 1177.se

**Oplægsholder:** Maria Hägglund, Associate Professor, Uppsala Universitet

**Resumé:** Patients or citizens are increasingly given online access to their electronic health records (EHR), both in the Nordic countries and internationally. In some countries, these are local implementations at a specific hospital or region, whereas others have national solutions. Differences in strategies and approaches have affected uptake and impact, and in several countries, the implementation progress has been slow because of legal constraints and concerns about, for example, security and privacy among medical professionals.

In the United States, the OpenNotes initiative for providing patients access to the clinicians' notes in the EHR began as a pilot and evaluation project that included 105 volunteer primary care physicians and their 19,000 patients. The initiative started in 2010 and has since spread throughout the United States. As of April 2021, a federal rule requires US health care providers to allow patients access to all health information in their EHR.

In Sweden, *Journalen* is the eHealth service that gives Swedish citizens online access to the EHR through the national patient portal 1177.se. *Journalen* accesses EHR information from different EHR systems used throughout Swedish health care organizations through a national health information exchange platform. Therefore, patients have one access point for all their health record information. Since the first Swedish region began providing its inhabitants web-based access to their health records in 2012, all other regions have connected to the national infrastructure and the PAEHR Journalen, with the last connection in March 2018. Different regions have however made different choices regarding how much of their information would be made available to patients, but all regions give access to records from both primary and secondary care. Record access includes clinician's free-text notes, lab results, diagnosis, information about referrals etc.

In this presentation, Maria Hägglund will give an overview of current adoption and use of the national patient portal and patients' access to their electronic health records in Sweden. She will also report on the results of an international survey study where data has been collected in Sweden, Norway, Finland and Estonia as part of the [NORDeHEALTH research project](#), focusing mainly on the Swedish results.

**Præsentation af oplægsholder:**

Maria Hägglund is an associate professor in health informatics and a senior lecturer in implementation science at the Uppsala MedTech Science & Innovation Centre, jointly funded by Uppsala University and Uppsala University Hospital. Her research focuses on user centered development of patient centered information and communication systems to support collaboration and patient empowerment. A special research interest is transparency and patients' access to their data. Within the Swedish research consortium DOME, she explores the impact of patients' access to their electronic health records (including notes) through the national Swedish patient portal. From a socio-technical perspective, it is highly relevant to compare and contrast different approaches to transparency, and Maria achieves this through international collaboration with the OpenNotes research group in the USA, with partners in the NordForsk financed project NORDeHEALTH, and through the EFMI working group Citizen Health Data. Maria is also associated to Karolinska Institutet and the Health Informatics Centre, where she was previously engaged as the programme director for the Global Master's Programme in Health Informatics.