

How can patients be in control of their healthcare if they are not in control of their online health information?

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Patient online access to health information

The Nordic Region is world-leading in providing its residents with comprehensive digital healthcare. Unlike in most European countries, Nordic patients have online access to their health records through patient portals, organised at a national level and provided free of charge. Through these portals, patients can retrieve their prescriptions and test results in a timely manner, view their diagnoses, and have access to the notes written by healthcare professionals in clinical consultations. **Research has repeatedly found that online access to these health data provides a variety of benefits to the patient**, such as improved health outcomes and increased trust in the care provided. Online health records, however, are far from perfected in the Nordic countries and research on their development continues.

The problem

Despite the many advances in the development of online health records, **Nordic patients still have unequal and fragmented access to and limited control over their online health information**. There is an ongoing shift towards more patient-centred care where the patient health record is viewed not only as a tool for clinicians to document the patient's medical history, but rather as a collaborative tool for shared decision-making. Yet, health information is challenging to access, find, and interpret, and patients have limited possibilities for interaction, contribution, and control of the information. This goes against the principle of the socially sustainable Nordic Region outlined in Vision 2030 and requires a combined effort to resolve.

We exemplify the problem by discussing three cases where increased patient access to and control over their health information is urgently needed. To evidence our arguments, we use data from a recent survey of 29,334 Nordic patients [1] and draw on our collective expertise in the NORDeHEALTH project to offer possible solutions [2].

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The NordForsk-funded project NORDeHEALTH (<https://nordehealth.eu/>, no. 100477) studies policies, practices and the experiences of patients and healthcare professionals relating to online health records in Sweden, Norway, Finland, and Estonia [1]. The team includes research, patient and clinician experts from the Nordic countries, as well as the UK and the USA.

CASE 1: Unequal access to information across the Nordic Region

While as a whole Nordic patients have a variety of health data available to them through national patient portals and online health records, this is not necessarily true on a regional level. In 2016, Swedish patients cited **the limited availability of information as the main cause of frustration in using their health records**. Six years later, the results from the 2022 NORDeHEALTH Patient Survey indicate that this problem persists, likely due to high variability in how the local healthcare providers manage health records. This is not unique to Sweden. In Finland, **44% of the reported negative experiences were due to unavailable information**, be it delayed due to local processing policies or missing altogether [3]. In addition, although the patient portals generally have fairly high usability, barriers to using the portals still exist, for example for people with cognitive or functional disabilities, new immigrants without an eID, or those who do not speak the official languages.

Equal access to healthcare is a key milestone when it comes to achieving a socially sustainable Nordic Region by 2030, but today, such equality does not apply to patients' online access to their health records. The autonomy of municipalities, regions and countries in the management of health records means that some patients may miss out simply due to their location or background.

Recommended solutions

- 1. Clear information on what is provided in the health record.** Some variability in information access will likely remain, and in national patient portals, it is essential to clearly present these differences to patients to reduce frustration and increase trust.
- 2. Design for inclusion.** Equal access to health information requires that everyone can access and use the national patient portal, regardless of abilities, language proficiency, and immigration status.
- 3. Introduce prescriptive and not suggestive legislation.** Legislation on what health information should be provided online to patients already exists. It is, however, often only a guideline for the local authorities.

CASE 2: Errors in the health record

Recent findings from NORDeHEALTH indicate that around **a third of Nordic patients find errors in their online health records** [4]. For some patient groups, this number is even higher: half of those who have experience interacting with the mental healthcare services report identifying a mistake [5]. When asked to consider its severity, **up to half of all patients judge the error as 'very serious'**. Described errors can range from relatively innocuous ones such as misspellings and false demographic details to more consequential ones: wrong medication dosage, missing allergies or incorrect diagnoses. Despite the high prevalence of reported errors and many of them considered severe, nearly half of the patients admit to not doing anything to rectify it [4,5]. A closer look at current implementation reveals possible causes.

At present, most Nordic patients can find erroneous information thanks to the widespread availability of online health records but they cannot follow up on it online. Rectification requests are instead made through calls to the administrative staff at the health centre or during their next clinical visit. None of these practices are sustainable. They increase the burden both on the patients, who may lack the capacity due to health or socioeconomic barriers, as well as on the healthcare professionals, whose resources have been strained under a heightened workload since the COVID-19 pandemic.

Recommended solutions

- 1. Enable patients to interact with errors online.** If a patient suspects an error, they should be able to flag it to their healthcare provider, request its correction and follow its processing in the online health record, without the need to resort to other services.
- 2. Enable patients to supplement their health records.** If a patient finds that important information is missing from their record (e.g. allergies), they should be able to contribute to it online using the same health record platform. Supplemented information could take the form of free-text comments or patient-gathered health data.
- 3. Introduce legislation ensuring patients' corrections and supplementations.** Patients' right to have their proposed corrections considered should be enabled by law. Legislation should state that healthcare professionals must take the patient's consideration into account to correct errors that have occurred.

CASE 3: Sharing your health record

Appointing a trusted person, such as a parent, guardian or caregiver, to access and manage one's health record is a practice referred to as proxy access. It is a crucial function for vulnerable patients, who may lack the capacity to use their own health records. Not all Nordic countries provide their patients with proxy access. In countries like Sweden, in the absence of this function, **patients are pushed to use insecure methods of sharing their health records**, such as sharing their login credentials.

Underage patients experience additional legislative challenges that may prevent parental proxy access. Recent NORDeHEALTH research has found **great variability between Nordic countries in the age when parental access is retracted and self-access is provided for minors** [3]. For example, parents in Finland have the possibility to access their child's records until adulthood, unlike parents in Sweden and Norway who lose their access when the child turns 13 and 12, respectively.

At present, unequal opportunities for proxy access contrast with the ambition of shared values promoted by the Nordic region. To achieve increased equality of care and improved health and well-being of vulnerable patients with caregiver needs, it is critical to combine efforts in developing secure portal systems, educating stakeholders, and developing shared principles for the allowance of proxy access.

Recommended solutions

- 1. Secure adult proxy access in all Nordic countries.** All adult citizens should have the right to grant proxy access to another trusted adult, who should then have the ability to securely manage their health records online.
- 2. Educate clinicians, caregivers, and patients on proxy access.** All parties involved in proxy access should be educated on its benefits, as well as how to safely and confidentially manage a health record to achieve the best care.
- 3. Introduce legislation enabling patients to share their health records with care partners.** Define a common policy within the Nordic countries for adult and parental proxy access, especially for minors aged between 12 to 18 years.

Summary

Today, Nordic patients experience great challenges in fully utilising the benefits of online access to their health records due to having insufficient control over them. Patients face information inequality between and within the Nordic countries, they find errors embedded in their medical records that are challenging to rectify, and they experience difficulties in sharing their records with trusted caregivers. Together, our region can solve these issues through socio-technical improvements in online health records and changes in legislation (see Figure 1).

Recommendations for patient control over online health records

GAIN EQUAL ACCESS	CORRECT ERRORS	SHARE RECORD
<ol style="list-style-type: none"> 1 Clear information on what is provided in the health record. 	<ol style="list-style-type: none"> 1 Enable patients to interact with errors online. 	<ol style="list-style-type: none"> 1 Secure adult proxy access in all Nordic countries.
<ol style="list-style-type: none"> 2 Design for inclusion. 	<ol style="list-style-type: none"> 2 Enable patients to supplement their health records online. 	<ol style="list-style-type: none"> 2 Educate clinicians, caregivers, and patients on proxy access.
<ol style="list-style-type: none"> 3 Legislative changes to enable these solutions on the local and national level. 		

Figure 1. Solutions to increasing patient control over their online health records.

PREPARED BY NORDeHEALTH

References

- 1 Hägglund M, Kharko A, Hagström J, Bärkås A, Blease C, Cajander Å, et al. The NORDeHEALTH 2022 Patient Survey: A cross-sectional survey of national patient portal users in Norway, Sweden, Finland, and Estonia. *JMIR Preprints*. 2023
- 2 Simola S, Hörhammer I, Xu Y, Bärkås A, Fagerlund AJ, Hagström J et al. Patients' Experiences of the National Patient Portal in Finland and its Usability: Cross-sectional Survey. *JMIR*. 2023
- 3 Bärkås A, Kharko A, Blease C, Cajander Å, Johansen Fagerlund A, et al. Errors, Omissions and Offences in the Health Record of Mental Healthcare Patients: Results from a Nationwide Survey in Sweden. *JMIR Preprints*. 2023
- 4 Wang B, Kristiansen E, Fagerlund AJ, Zanaboni P, Hägglund M, Bärkås A et al. Patient Experiences and Perceptions with Online Access to Electronic Health Records in Norway: Cross-Sectional Survey Comparing Mental Health and Somatic Patients. *JMIR Preprints*. 2023
- 5 Hagström J, Scandurra I, Moll J, Blease C, Haage B, Hörhammer I, Hägglund M. Minor and parental access to electronic health records: Differences across four countries. *IOS Press*. 2023