MEDINFO 2023 — The Future Is Accessible J. Bichel-Findlay et al. (Eds.) © 2024 International Medical Informatics Association (IMIA) and IOS Press. This article is published online with Open Access by IOS Press and distributed under the terms of the Creative Commons Attribution Non-Commercial License 4.0 (CC BY-NC 4.0). doi:10.3233/SHTI231014

Citizens Access to Health Information in National Portals in the Nordic Countries

Christian NØHR^{a,1}, Heidi GILSTAD^b, Tuulikki VEHKO^{c,} Jarmo REPONEN^{d,e}, Sidsel VILLUMSEN^f, Gudrun A. HARDARDOTTIR^g, Rune PEDERSEN^h, Vivian VIMARLUNDⁱ and Sabine KOCH^j

^a Danish Center for Health Informatics, Dept. of Planning, Aalborg University, Denmark

^b SEKOM, Dept. of Language and Literature, Norwegian University of Science and Technology, Norway

^c Health and Social Service System Research, Finnish Institute for Health and Welfare (THL), Finland

^d Research Unit of Medical Imaging, Physics and Technology, Faculty of Medicine, University of Oulu, Finland

^e Oulu University Hospital (MRC Oulu), Finland

^fDepartment of Psychology, Aarhus University, Denmark

^gDirectorate of Health, National Centre for eHealth, Iceland

^hNorwegian Center for E-health Research, Tromsø, Norway

ⁱDept. of Information and Computer Science, Linköping University, Sweden ^jDept. of Learning, Informatics, Management and Ethics, Karolinska Institutet, Sweden ORCiD ID: Christian Nøhr <u>https://orcid.org/0000-0003-1299-7365</u>, Heidi Gilstad <u>https://orcid.org/0000-0003-2534-1613</u>, Tuulikki Vehko <u>https://orcid.org/0000-0002-0034-8379</u>, Jarmo Reponen <u>https://orcid.org/0000-0003-2306-3111</u>, Sidsel Villumsen <u>https://orcid.org/0000-0003-0832-0861</u>, Vivian Vimarlund <u>https://orcid.org/0000-0002-</u> 6491-7198, Sabine Koch https://orcid.org/0000-0001-7144-8740

> Abstract. National eHealth portals for citizens are available in the five Nordic countries. This study describes and compares the Nordic citizen portals and identifies variations in content access and functionality. The findings suggest that availability of information and services depend on the organisation of the health system, the connection to national health information exchange platforms and incentives for providing data and services.

Keywords. Consumer health informatics, eHealth portals, eHealth monitoring

1. Introduction

Citizen eHealth portals are believed to have the potential to empower citizens to take a more active role in their health and well-being through digital access to general health information and on-line health services [1,2]. The Nordic countries have a history of using information and communication technology in healthcare, building up national registries [3], and providing possibilities for health information exchange at a national

¹ Corresponding Author: Christian Nøhr, email: cgn@plan.aau.dk

level [4]. With most health-related data being digital, both functionalities and content of emerging on-line health services provided through eHealth portals become important. The Nordic eHealth portals were launched at different points in time and developed in different ways but are expected to include comparable content and functionality. The aim of this study was to describe the national eHealth portals in five Nordic countries, compare their functionalities, elicit reasons for differences and commonalities.

2. Methods

Data collection and analysis was done by the authors, who are all members of the Nordic eHealth Research Network (NeRN) [5], representing deep knowledge of the digital health infrastructures in the five Nordic countries (Denmark, Finland, Iceland, Norway, and Sweden). Data about portal content and functionality for each country were collected by two authors from that country (except Iceland that is represented only by one author). The author-pairs provided a written description of their national portal and listed content and functionalities. During a meeting with all authors, these lists were converted into a table which was iterated five times until consensus on the homogeneity and granularity of the table items was reached. The table was then used as basis for the country comparison where reasons for differences and commonalities were discussed among all authors.

3. Results

The national eHealth portals are described in the following, and an overview of content and functionality is presented in Table 1.

	Denmark	Finland	Iceland	Norway	Sweden
Background					
Portal name	sundhed.dk	kanta.fi	heilsuvera.is	helsenorge.no	1177.se
Year started	2003	2007	2014	2011	2013
Content (access to)					
Hospital appointments	YES	NO	PARTLY	PARTLY	YES
Referrals	YES	YES	Yes	PARTLY	PARTLY
Lab test results	YES	YES	PARTLY	YES	PARTLY
Daily notes (hospital)	YES	PARTLY	NO	YES	YES
Daily notes (GP)	PARTLY	PARTLY	No	PARTLY	YES
Medication record	PARTLY	PARTLY	YES	YES	PARTLY
Medical image descriptions	YES	YES	NO	YES	PARTLY
Healthcare visits	PARTLY	PARTLY	YES	YES	YES
Immunization	PARTLY	PARTLY	Yes	YES	PARTLY
Critical care information	YES	PARTLY	NO	YES	YES
Allergy information	NO	YES	YES	YES	YES
Maternal health record	YES	YES	YES	YES	NO
Functionality					
Appointment booking	YES	NO	YES	YES	YES
Citizens can add own info	PARTLY	PARTLY	PARTLY	YES	PARTLY
Health and care plan	NO	PARTLY	NO	NO	PARTLY
Will expression	YES	YES	YES	YES	NO
Request COVID-19 test	YES	PARTLY	YES	YES	YES
Request and print sickness certificate	NO	PARTLY	YES	PARTLY	YES

Table 1. Nordic citizen eHealth portals - content and functionality.

3.1. Denmark – sundhed.dk

Sundhed.dk is the unified Danish eHealth Portal providing access to information about all the Danish healthcare services. Since its launch in 2003, sundhed.dk has provided functionalities such as quality assured health information, access to medical records and medication, and an overview of the Danish healthcare system. Sundhed.dk creates linkages between existing data sources and facilitates communication between healthcare providers and citizens. The initiative to establish The Danish eHealth Portal was taken by the Ass. of County Councils in Denmark, the Ministry of Interior and Health, and others in 2001 [6]. While the portal has been steadily used by general practitioners (GPs), a general shift was noted in the citizens' use of the portal during 2010. As the portal was central to the COVID-19 response, usage increased during this time.

3.2. Finland – kanta.fi

Kanta services Finland includes a family of information exchange and storage services that are used by citizens and social welfare and healthcare service providers, connecting public and private sectors. My Kanta Pages is the citizens' portal component within the services, providing a secure access to e.g., electronic prescriptions, records related to treatment, laboratory tests, and X-ray examination results. The citizens can manage their consent to the information access as well as their living wills and organ donation wills. An immunization view contains all new immunizations, a process boosted by the need of vaccination certificates related to COVID-19. In Finland, the Ministry of Social Affairs and Health has steered the implementation of Kanta services since 2007. The Kanta services are built jointly in cooperation with several national actors and together with health and social care service providers, pharmacies, and system suppliers [7].

3.3. Iceland – heilsuvera.is

Heilsuvera is the national citizen health portal in Iceland. The initiative to develop the portal was from the Directorate of Health which received a grant from the government in 2013 to develop a secure access for citizens to their own health record. The eHealth portal was first launched in 2014 and has been under constant development since. Available services today include, but are not limited to, medication renewal, prescriptions, vaccinations, secure messaging with health professionals, e-bookings, PRO questionnaires, treatment instructions, maternal health record, and doctors' referrals to name a few. Heilsuvera is managed by the Directorate of Health.

3.4. Norway - helsenorge.no

Helsenorge.no was established in 2011 by the eHealth department of the Directorate of Health and is the national citizen portal for access to most health services in Norway. The portal securely links to personalized health information, such as messages, referrals, prescriptions, vaccinations, patient record, and test results. The citizen can also access generalized information about patient services and rights, registers, and research. The portal offers links to other national health and welfare related services. Helsenorge.no is available for all citizens with a national ID number, but the content input and quality depend on the regional and local health service providers.

3.5. Sweden – 1177.se

Healthcare Guide online, 1177.se, is Sweden's national portal for healthcare information, advice, and access to e-services for health and healthcare. Healthcare Guide 1177 is provided to the general public jointly by all Swedish county councils and regions. To assure consistent, uniform information about health issues and their management on openly accessible pages, Healthcare Guide 1177 builds upon a common quality-assured medical database and comprises healthcare advice via telephone and Internet. Citizens are provided with individual access to administrative services such as managing appointments and sick certificates; to clinical services such as accessing medical records, order healthcare tests or accessing Internet therapy; and to prescription services to access their medication lists and manage prescriptions [8].

3.6. Comparison of Content and Functionality

The Nordic eHealth portals give citizens access to general health information and, through secure login, access to different patient specific administrative and communication services, clinical services, and prescription services. Table 1 shows that most patient data are available in all the Nordic countries. Due to regional decision making, some data sets are however either not or only partly available.

PARTLY in Table 1 is to be interpreted slightly differently across the Nordic countries, i.e., private healthcare providers are not obliged to share information with the national portal or in regionally divided countries, all functionalities may not be available in all regions. Daily notes from hospitals and GPs vary in detail and comprehensiveness. In some countries only prescription medication is noted entailing in-patient medication is not or only partially noted as well as access to other information is dependent on their implementation in the local information systems. Citizens access to adding own information to the national portal varies considerably, yet this field is advancing, i.e., in Finland supported by new legislative acts.

4. Discussion

Citizens in the Nordic countries have access to their patient data and to different eHealth services through national portals. The main factors shaping availability of data and services are: 1) the type of healthcare system: centralized eHealth governance (Finland, Denmark and Iceland) vs regional decision making (Norway and Sweden), 2) who is connected to national health information exchange platforms (few private actors, but all public actors (Sweden), public hospitals but not mandatory for private healthcare providers (Denmark), mandatory to all public hospitals and primary health care centres as well as to the private service providers using an electronic medical record systems (Finland), 3) connection of hospitals to health information exchange platforms (Denmark and Finland), 4) incentives for providing data and services from the healthcare side. Denmark and Iceland were early to reimburse primary care for secure messaging and in Finland, the various sectors providing from the information exchange, this being an incentive to connect to and provide information to the national system, the other being legislation.

Albeit many similarities, both technical implementation and governance of the national portals differ. For instance, it appears that citizens in some countries can add own information from vital measurements. These differences are not due to technical difficulties but political decisions. Due to variations in the structure of health care organization models, not all the Nordic Countries include the same functionalities in their national health portal even though such functionalities are otherwise available at the national level. Availability and content follow policies and strategic plans for their implementation in the respective countries. Not least regarding incentive models and reimbursement, the Nordic countries can learn from each other. It is however important that updating of policies and development of citizen eHealth services goes hand-in-hand to make well informed decisions and provide the right services.

5. Conclusions

The comparison and analysis of five national eHealth portals in the Nordic countries shows that political decisions and regional policies, type of healthcare system (centralized/decentralized) as well as reimbursement systems have a major impact on technical implementation and use. This leads to differences in both availability of data and services, to different priorities in the choice of services between countries, and to unequal availability of services within a country. These insights can inform future policy making regarding national eHealth portals for citizens.

References

- Fraccaro P, Vigo M, Balatsoukas P, Buchan IE, Peek N, Van Der Veer SN. Patient portal adoption rates: a systematic literature review and meta-analysis. Stud Health Technol Inform. 2017;245(2017), 79-83, doi: 10.3233/978-1-61499-830-3-79.
- [2] Essén A, Scandurra I, Gerrits R, Humphrey G, Johansen MA, Kierkegaard P, Koskinen J, Liaw ST, Odeh S, Ross P, Ancker JS. Patient access to electronic health records: differences across ten countries. Health Policy Technol. 2018 Mar;7(1):44-56, doi: 10.1016/j.hlpt.2017.11.003.
- [3] Laugesen K, Ludvigsson JF, Schmidt M, Gissler M, Valdimarsdottir UA, Lunde A, Sørensen HT. Nordic health registry-based research: a review of health care systems and key registries. Clin Epidemiol. 2021 Jul;13:533-54, doi: 10.2147/clep.s314959.
- [4] Nøhr C, Faxvaag A, Tsai CH, Harðardóttir GA, Hyppönen H, Andreassen HK, Gilstad H, Jónsson H, Reponen J, Kaipio J, Øvlisen MV. Nordic eHealth benchmarking: towards evidence informed policies; 2020 May, doi: 10.6027/temanord2020-505.
- [5] Nordic eHealth Research Network (NeRN), Finnish Institute of Health and Welfare, https://thl.fi/en/web/thlfi-en/research-and-development/research-and-projects/nordic-ehealth-researchnetwork-nern (Accessed 29.11.2022).
- [6] Jensen TB, Thorseng AA. Building national healthcare infrastructure: the case of the Danish e-health portal. In: Aanestad M, Grisot M, Hanseth O, Vassilakopoulou P, (eds). Information infrastructures within European health care. Health Informatics. Cham: Springer; 2017. p.209-24, doi: <u>10.1007/978-3-319-51020-0_13</u>.
- [7] V. Jormanainen, K. Parhiala, A. Niemi, M. Erhola, I. Keskimäki, and M. Kaila, Half of the Finnish population accessed their own data: comprehensive access to personal health information online is a cornerstone of digital revolution in Finnish health and social care, Finnish Journal of eHealth and eWelfare 11 (2019), 298–310.
- [8] Jormanainen V, Parhiala K, Niemi A, Erhola M, Keskimäki I, Kaila M. Half of the Finnish population accessed their own data: comprehensive access to personal health information online is a corner-stone of digital revolution in Finnish health and social care. FinJeHeW. 2019 Nov;11(4):298-310, doi: 10.23996/fjhw.83323.
- [9] Om 1177, Inera, https://www.inera.se/tjanster/1177/om-1177/ (Accessed 29.11.2022).