

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

Vesa Jormanainen¹, MD, MSc, Kimmo Parhiala¹, MSocSc, Anu Niemi¹, MD, Marina Erhola¹, MD, MQI, PhD, Ilmo Keskimäki^{1,2}, MD, PhD, Minna Kaila^{3,4}, MD, PhD

¹ Finnish National Institute for Health and Welfare (THL), Helsinki, Finland; ² University of Tampere, Tampere, Finland; ³ University of Helsinki, Helsinki, Finland; ⁴ Helsinki University Hospital, Helsinki, Finland

Vesa Jormanainen, Chief Specialist, Social and Health Systems Research, Finnish National Institute for Health and Welfare (THL), P.O. Box 30, FI-00271 Helsinki, FINLAND. Email: vesa.jormanainen@thl.fi

Abstract

In Finland, the implementation of the national Kanta services' second phase was carried out step by step from May 2010 to December 2017. My Kanta Pages, launched in 2010, is an online service where citizens can browse their own health information recorded in the Prescription Centre and the Patient Data Repository regardless of whether the healthcare services they had used were public or private. It is the patient accessible national electronic health records in Finland (PAEHR).

The study objective was to investigate the use of the national PAEHR by using indicator data from 2010 to 2018.

Cumulatively 2.8 million (M) persons (51% of the Finnish population, and 63% of the adults at least 18 year old) had accessed the PAEHR 23.2M times (49.2M sign-ins) by 31 December 2018. Altogether, 6.0M e-prescription renewal request were sent to healthcare via the PAEHR by 31 December 2018. Patient Data Management Service was implemented as part of the Patient Data Repository. By 31 December 2018, the Patient Data Management Service had records of 6.3M information notices, 3.3M consents and 93,732 refusals (consent restrictions). In addition, the Patient Data Management Service had records of 467,055 organ donation testaments and 93,484 living wills.

Half of the Finnish population in general, and two out of three adults had used the national PAEHR by 31 December 2018. Since nine years after its launch, the adults' use of the Finnish national PAEHR is still increasing and is approaching 50% annual use.

Keywords: access to information, patient internet portal, electronic health records, information system

Introduction

Many European health systems have recognized the transformative potential of digital health services for improving care delivery and reducing costs [1]. From 2006 to 2010, European Union member states reported considerable increase in national e-health activities but still, patients had rarely access to their own medication profiles or were able to reorder certain repeat medications themselves, e.g. via the web [2]. In 2019 Finland, Sweden, the Netherlands, and Denmark scored highest according to the Digital Economy and Society Index of the European Commission [3], followed by the United Kingdom, Luxembourg, Ireland, Estonia and Belgium.

Patients are offered access to their own health data on a national level only in a few countries, such as Australia, Canada, Denmark, Estonia, Finland, France, Iceland, New Zealand, Norway, Scotland, Singapore and Sweden [4]. Easy access to personal health information has long been on the wish lists of patients and their advocates, and modern health information technology, internet and secure patient accessible electronic health records (PAEHR) may dramatically increase possibilities for patients' access to their own data [5–8].

Access to health records improves quality of care, shared care management, with patients using their records to improve interactions with healthcare providers, decision-making about their health [7,9–12]. Access to PAEHR is likely to save time for patients and practices in primary healthcare [13]. In a year-long quasi-experimental trial among 105 primary care practitioners and their 13,564 patients, the patients accessed their visit notes frequently, a large majority reported clinically relevant benefits and minimal concerns, and virtually all patients wanted the practice to continue [5,6]. Concerns of professionals about privacy were unrealized and those about workload increase were only partly corroborated according to a systematic review [12]. Physicians' experiences with the usability of currently used electronic health record (EHR) systems and changes in their perceptions did not improve between 2010 and 2017 [14].

A nationally shared, widely accessible PAEHR system has powerful symbolic meaning; it may or may not be perceived as improving quality and safety of care. Alternatively a PAEHR can be seen as a threat to patient confidentiality or the traditional role of the physician or the nurse [15]. Online e-services in healthcare and social welfare services are usually PAEHRs that are owned by healthcare organizations [16,17]. However, introduction of a PAEHR alone does not guarantee its wide use among patients with a diagnosis [18,19]. In 2007, e-services that the adult (at least 18 year old) Finns who responded in a population survey wished for, such as access to laboratory test information, appointment scheduling or repeated prescription renewal, were in short and there was no possibility to view electronic medical records (EMR) or EHR [20]. In 2014 among respondents in a population survey, the most asked online services were still an access to laboratory and medical imaging results, patient records, prescription data and prescription renewal [21]. In contrast, the follow-up survey respondents in 2017 had already used multiple such online services which they also considered useful in general [22].

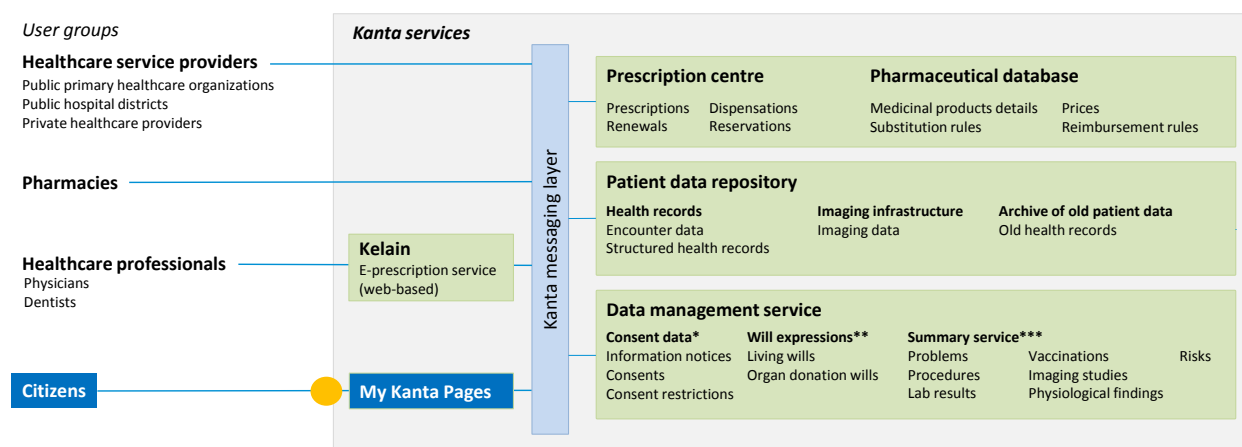
There is also a geographical aspect of information and communication technologies: telephone and internet may be well suited for health education in rural areas [23,24], but not necessarily for everyone [25]. Living in a rural versus urban area may have implications on technology adoption. In Sweden, older adults living in rural areas use internet less than their urban counterparts [26].

Kaiser Permanente, a non-profit healthcare organization in the USA, began offering online healthcare services in 1996 [27]. Functionalities, such as prescription refill, online appointment transactions, facility directory and health encyclopaedia visits consistently rank among the six most visited and used features. Sweden became one of the first countries to use e-prescriptions in 1983, and patients as well as physicians generally have expressed satisfaction with the e-health system [8,28–31]. Electronic patient journals have been available for patients since 2012 but each region decides what information is shown. Denmark is an early adopter of health information technology [2] and, launched the Danish

national PAEHR sundhed.dk in 2003 [4] and the E-Journal national repository of record information from all public hospitals in 2007 [32].

Finland also has a long history of using information technology in healthcare [33,34]. The issuing of e-prescriptions was made obligatory in public healthcare in 2013 and in private healthcare in 2015. Since January 2017, all healthcare providers are obliged to use the e-prescription system [35]. Community pharmacy customers are familiar and very satisfied with the national service [36,37], and general practitioners report that e-prescribing has improved their patient medication management [38,39]. Finnish health professionals have positive expectations about the PAEHR [40].

Kanta services is the name of the Finnish national digital data system services that form a unique service entity based on legislation effective since July 2007 [34]. The current main services are described in Figure 1. Since the Finnish national PAEHR does not have a stand-alone data of its own, information from community pharmacies (medicine dispensations) and e-prescriptions registered in healthcare are shown in the PAEHR together with health data registered to the Patient Data Repository. The Prescription Centre is in mandatory use nationwide since January 2017 whereas the Patient Data Repository is in use in Mainland Finland excluding the Åland Islands.



* In Consent data section, information about the fact that the patient has been informed of the nationwide data system services (information notices) is recorded. A person can read the information and give one's consent to view the data so that the people who are treating one can view his/her medical records; this is recorded (consents). One can also give one's refusal to share one's e-prescription or patient record data, which use recorded (consent restrictions)

** In Will expressions section, a citizen can set up a living will and/or organ donation testament

*** In Summary service section, a citizen's current health problems (such as elevated blood pressure) and risks (such as smoking) are displayed based on their appearance in the citizen's health records in addition to (surgical or else) procedures, laboratory test results, vaccinations, imaging reports and physiological findings (such as blood pressure measurement results)

Figure 1. A simplified architecture of user groups of the Finnish national Kanta services and patient accessible electronic health records (My Kanta Pages).

All Finnish residents with a Finnish personal identity number and an access to electronic identification are able to use the PAEHR [34,41]. With the help of the PAEHR, the users can monitor the retrieval and submission of one's own information, view e-prescriptions and medication purchases, request prescription medication renewal, view personal health data, give consents and consent restrictions (refusals) to share one's e-

prescription and patient data, and set up a living will and/or organ donation testament. Parents and guardians can view medical records of their children younger than 10 years of age. All healthcare providers who use electronic patient record systems are obliged by law to send prescription and health data to the Kanta services and these data are visible in the PAEHR. Thus, information from organizations that do not use electronic

patient records, are not visible in the PAEHR. Healthcare professionals record data in their electronic patient record systems, which transmit these data encrypted in a standardized format into the Kanta services. Otherwise, the professionals can access their own health data as citizens do via the PAEHR. Practically the entire electronic patient journals are available for patients through the PAEHR. All medicine prescriptions except medicines prescribed during hospital admissions are available through the PAEHR.

Patients are offered access to their own health data on a national level only in a few countries, such Finland. However, a nationally shared PAEHR does not guarantee its wide use among patients. In addition, since Finland is the most sparsely populated EU member state, it is of utmost importance to study the geographical aspects of online services use such as the national PAEHR.

Our study objective was to investigate, for the first time, the nationwide use of My Kanta Pages in Primary Healthcare Centres, 21 Hospital Districts and five University Hospital Catchment Areas in a study period from 2010 to 2018. The specific research questions were:

- How monthly and annual indicators of My Kanta Pages use have evolved?
- How do proportions of adult users vary between Primary Healthcare Centres, Hospital Districts and University Hospital Catchment Areas?
- How monthly and annual repeated e-prescription renewal requests sent to healthcare have evolved?
- How many information management notifications (information notices, consents and consent restrictions) and declarations of intent (organ donation testaments, living wills) were stored to the service?

Materials and methods

Finland is a sparsely populated country of 5.5 million inhabitants who live in an area of 338,145 km² with an average population density of 18 persons per km². In addition to Parliament and the Ministries, the admin-

istration comprises regional and local level governance with six administrative regions, including the autonomous Åland Islands. In June 2019, there were 311 self-governing municipalities, 16 of which in the Åland Islands. Finland has a healthcare system with a highly decentralized administrative structure, multiple financing sources and three provisional channels for statutory services in first-contact care: the municipal system, the national health insurance system and occupational healthcare. In addition to the public sector, many private enterprises and non-governmental organizations also provide services. Finnish health policy seeks to incorporate Health in All policies into all aspects of public decision-making. The main goals are to promote population health and welfare, reduce health inequalities, ensure universal access to services, improve quality and increase responsiveness of the system. Information to Support Well-being and Service Renewal – eHealth and eSocial Strategy 2020 was adopted in 2015 with the goal of improving information management and expanding the volume of online services in healthcare and social welfare services. All patient information in Finland is now in electronic format and electronic patient records are used widely in both the public and private sector.

The total number of all the PAEHR users in 2018 were found out by including each unique personal identification code only once in calculations. Monthly numbers of PAEHR use were calculated as sums of total numbers of sign-ins to the PAEHR. Monthly numbers of the PAEHR use were also calculated for repeated e-prescription renewal requests, information management notifications (information notices, consents and consent restrictions) and declarations of intent (organ donation testaments and living wills). The Finnish Social Insurance Institution (Kela) is the record holder of the PAEHR, and research data were received from its Kanta Services Unit.

Municipal population data were collected from the Statistics Finland's StatFin public online services. We used adult population (18 years or older) at 31 December 2017 as a common denominator in the analyses. We excluded data on 39,226 children (younger than 18 years of age) who had accessed the PAEHR by using

their own authentication codes and who made up 1.4% of persons that had used the portal at least once by 31 December 2018.

Results are presented mainly in counts and proportions, some results also in maps. We define monthly signed-in persons as sum of person identification codes, and sign-ins as sum of portal sign-ins during the month. The annual sum of signed-in persons include each unique personal identification code only once in calculations. In Figure 3 the basemap borders present Primary Healthcare Centre (white colour) and Hospital District borders (black colour; outer borders of the Primary Healthcare Centres in the same Hospital District).

Results

Prescription and medication dispensation information from Prescription Centre that is shown in the PAEHR were recorded nationwide by all (100%) community pharmacies and public healthcare providers, and by 1,331 private healthcare providers. In addition, all (100%) public and 1,330 private healthcare providers recorded health information in Patient Data Repository at the end of 2018.

Cumulatively 2.8 million (M) persons (51% of the Finnish population, and 63% of the adults) had signed-in 49.2M times into the PAEHR from May 2010 to 31 December 2018. Altogether, 6.0M e-prescription renewal requests were sent to healthcare providers.

Patient Data Management Service was implemented as part of the Patient Data Repository. By 31 December 2018, Patient Data Management Service had records of 6.3M information notices, 3.3M consents and 93,732 consent restrictions (refusals) (see note in Figure 1). In addition, there were records of 467,055 organ donation testaments and 93,484 living wills.

Altogether 2.19M adults (49% of the adults) in 2018 logged 16.8M times into the PAEHR. Daily mean was 18,610 signed-ins (Figure 2). Proportions of the PAEHR use in 2018 varied between age groups: it was 1.9% among persons younger than 18 years of age, whereas some 50% among working age (18–65-year-olds) population. The user proportion was 50.7% among 18–35-year-olds, 48.9% among 36–50-year-olds and 51.1% among 51–65-year-olds. Interestingly 36.7% of persons older than 65 years of age had also used the patient portal.

The adults' use of the PAEHR varied by 142 Primary Healthcare Centres (21–62%), 21 Hospital Districts (21–53%) (Table 1) and five University Hospital Catchment Areas (45–51%) (Figure 3). The three highest user proportions among Primary Healthcare Centres were 61.7% (Kempele, population 12,508), 57.7% (Liminka, population 6,121) and 56.6% (Muhos, population 6,366), all in the Northern Ostrobothnia Hospital District and Oulu University Hospital Catchment Area. In 2017, there were two Primary Healthcare Centres in which the user proportion was higher than 50% whereas in 2018 the number was 29 Primary Health Centres (20% of the 142 Primary Healthcare Centres).

The adults' user proportions among the Hospital Districts varied between 21–53% in 2018. The highest user proportions were in Northern Ostrobothnia (53%), Helsinki-Uusimaa (53%), Northern Savonia (51%) and Central Ostrobothnia (51%), and the lowest in the Åland Islands (21%) (Table 1, Figure 3).

Adult user proportions varied among the University Hospital Catchment Areas in 2018, between 45–51% and was highest in Oulu and Helsinki-Uusimaa University Hospital Catchment Areas, and lowest (45%) in Turku University Hospital Catchment Area (Table 1).

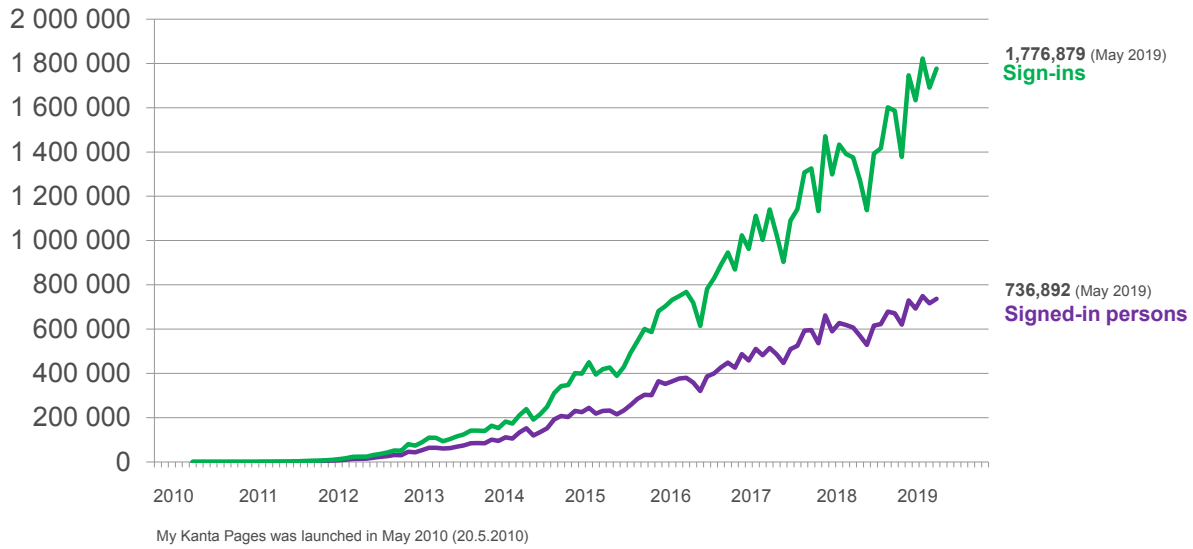


Figure 2. Numbers of signed-in persons and sign-ins into the Finnish national patient accessible electronic health records (My Kanta Pages) by month from May 2010 to May 2019.

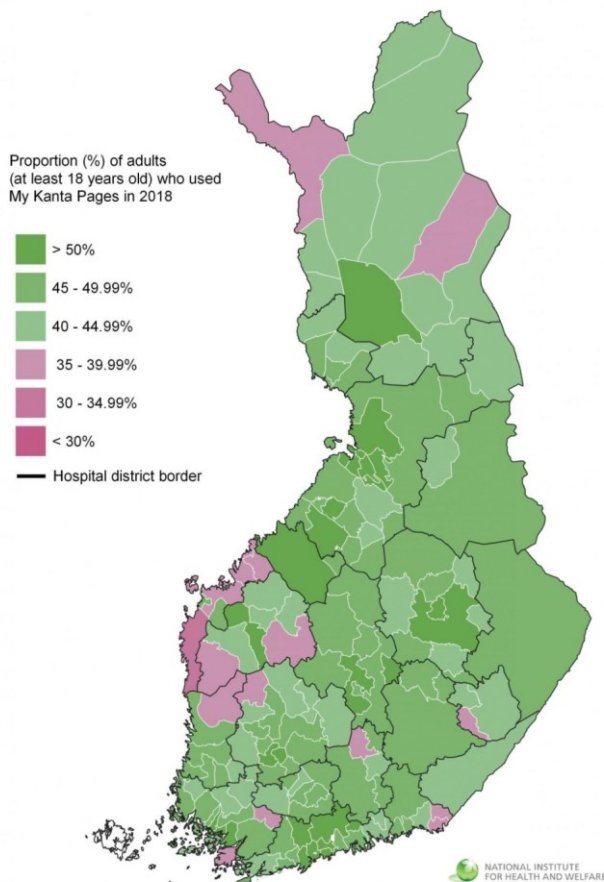


Figure 3. Proportion (%) of adults (at least 18 years old) who used the Finnish national patient accessible electronic health records (My Kanta Pages) in 2018 by primary healthcare centres by hospital districts.

Table 1. Proportion (%) of adults (at least 18 years old) who used the Finnish national patient accessible electronic health records (My Kanta Pages) in 2018 by the five University Hospital Catchment Areas and the 21 Hospital Districts (including the Åland Islands).

	Adult users		Population
	%	n	N
Helsinki University Hospital	51.2	805 467	1 571 691
Helsinki-Uusimaa Hospital District	52.6	696 652	1 323 381
Kymenlaakso Hospital District	45.0	63 016	140 147
Southern Karelia Hospital District	42.3	45 799	108 163
Tampere University Hospital	47.4	426 382	899 274
Pirkanmaa Hospital District	48.1	207 118	430 372
Päijät-Häme Hospital District	48.9	84 970	173 690
Southern Ostrobothnia Hospital District	45.3	70 509	155 519
Kanta-Häme Hospital District	45.7	63 785	139 693
Turku University Hospital	45.4	332 189	732 206
Varsinais-Suomi Hospital District	48.3	189 945	393 184
Satakunta Hospital District	45.7	82 642	180 690
Vaasa Hospital District	40.6	54 633	134 611
Åland Islands Hospital District	20.9	4 969	23 721
Kuopio University Hospital	49.1	325 676	663 631
Keski-Suomi Hospital District	49.6	100 855	203 230
Northern Savonia Hospital District	51.0	102 963	201 968
Northern Karelia Hospital District	48.7	67 078	137 696
Southern Savonia Hospital District	46.0	39 107	84 954
Eastern Savonia Hospital District	43.8	15 673	35 783
Oulu University Hospital	51.2	297 127	579 977
Northern Ostrobothnia Hospital District	53.4	166 532	312 023
Lapland Hospital District	48.6	46 944	96 528
Middle Ostrobothnia Hospital District	50.7	30 664	60 495
Kainuu Hospital District	49.2	30 074	61 134
Länsi-Pohja Hospital District	46.0	22 913	49 797
All	49.2	2 186 841	4 446 779



Figure 4. Number of e-prescription renewal requests sent to healthcare via the Finnish patient accessible electronic health records (My Kanta Pages) by month from November 2015 to May 2019.

Online e-prescription renewal request service via the PAEHR was launched in November 2015. The service can be used for an e-prescription in which a purchase has already been done at least once in a community pharmacy. In total, 2.1M prescription renewal requests in 2018 were submitted to healthcare (Figure 4). Monthly number of transmitted e-prescription renewal requests is approaching 250,000.

The Patient Data Management Service, part of the Patient Data Repository, was launched in May 2010. The Patient Data Management Service had records of 6.3M personal information notices in 2018. Altogether 3.3M persons gave their permission for their patient health records use by other record holders than where the records were born in 2018. By the end of 2018, a total of 93,732 persons had at least once set a consent restriction (refusal) to let their patient records to be processed from the Patient Data Repository.

Discussion

Our study objective was to investigate, for the first time, the nationwide use of the Finnish national patient

accessible electronic health records (My Kanta Pages) in 142 Primary Healthcare Centres, 21 Hospital Districts and five University Hospital Catchment Areas in a study period from 2010 to 2018. We found that cumulatively almost two out of three adults had signed-in to the PAEHR by end-2018. In 2018, almost half of the adults used the PAEHR to access his or her health data – a universal patient portal produced and financed by the state, use of which is free-of-charge. The variation between proportions of adult users of the PAEHR in 2018 was observed largest in analyses where the numbers of areas were the largest. However, adult user proportions in 2018 varied only little between the University Hospital Catchment Areas and Hospital Districts in the mainland Finland.

Our study has several strengths and weaknesses. We had complete numbers of the PAEHR users by municipalities with some information about the user population nationwide in 2018. These data have been published online in kanta.fi and the data were utilized efficiently. However, we lacked data and information about the adult user characteristics by municipality, such as age and gender or, say, their classification into

10-year age groups by gender. In addition, we would like to have information and characteristics of the municipalities and Primary Healthcare Centres, such as disease or illness prevalence. These would be needed in order to explain differences in adult PAEHR user proportions between municipalities, Primary Healthcare Centres, Hospital Districts and University Hospital Catchment Areas.

Even though we have reported large-scale use of our national PAEHR, we are only in the beginning of getting better information and knowledge to understand reasons behind the use among various user groups. We have only recently started to probe carefully service usability, content and data needs of our various customers. Finns have already shown their vast interest in the PAEHR, which is also one of the enablers to renewal and transformation of healthcare and social welfare processes. Systematic changes in working processes in working units require well managed and executed improvement efforts and implementation of new service delivery pathways. All the multidisciplinary personnel – managers taking the lead – must be committed to changes for better patient care.

A nationally shared, widely used PAEHR has powerful symbolic meaning [15] and they have been developed, launched and used in many countries, including Finland [4]. However, the PAEHRs are rarely nationwide [16,17,41]. When new functionalities, such as requests to refill prescriptions, are launched in the PAEHR, the use of the PAEHR increases [27]. Kaiser Permanente's member registrations on its member website grew significantly when refill prescription service was added and especially when lab test viewing service was launched 10 years after the online service was launched. Similar functionalities have been developed in PAEHRs in other countries [41].

In Finland from 2010 to 2018, however, not all the requested functionalities of the national PAEHR are in production, yet. The Finns have asked in surveys for a number of online services, such as laboratory results, appointment scheduling and prescription renewal [20,21]. An access to laboratory and medical imaging results, patient records, prescription data and prescrip-

tion renewal, but not online appointment scheduling are already available for the users in the Finnish national PAEHR. The expansion of the PAEHR functionalities to personal health records which users can record themselves in 2018 (Kanta PHR) may potentially bring significant added value to citizens, service developers and to Kanta services.

According to population surveys, at least some kind of online service was used by 58% of respondents in 2014 and 68% in 2017 in Finland [21,22]. Two out of three respondents reported that their greatest barrier for online service use was that the face-to-face appointment could not be replaced by an online appointment. Patients' need to be able to take care of their social and healthcare matters face-to-face must be emphasized in future as well. However, all appointments do not necessarily have to take place in a same room or place. Scheduled face-to-face (control) meetings or contacts agreed may well be put to channels that use online interaction.

Since the PAEHR, the Prescription Centre and the Patient Data Repository were launched, the users are given a wealth of information regarding their own prescriptions and medication dispensing events [35]. Information for patients to view in the PAEHR is recorded in all community pharmacies and public healthcare providers, but still not by every private healthcare provider that have not subscribed the services. Launching these data services was a considerable, large-scale, multi-partner and public-private joint endeavour. The introduction of nationally standardized information security procedures and working practices was a strongly appreciated "side product".

Use of digital online services, such as the PAEHRs, can enhance citizens' or patients' control of personal space, alleviate anxiety without any negative impact [1]. Involving patients in their own care by allowing them an access to their PAEHR data is a trend seen in many places [4]. Easy access to personal health information has long been on the 'wish lists' of patients and their advocates [5–8,27]. Record access improves shared care management [7,9–12]. PAEHR access is likely to

save time for patients and practices in primary healthcare [13].

Using an online service in general requires basic information technology skills and motivation from the users as well as relevant equipment, an internet connection and health data literacy [23]. The information available for citizens or patients may also generate anxiety and misunderstanding by letting information, such as laboratory results, to be seen without a possibility to discussion with a healthcare professional. Such situations may arise, for example, when laboratory tests were ordered to exclude cancer in differential diagnostics and no time delay for these results to be seen was used. In case no time delay was used, the patient will see only that cancer tests were performed and their results are shown without any explanation.

We found variation in the PAEHR user proportions in 2018. We observed that the smaller the regional area analyzed, the bigger the variation in proportion of adult users. This is a typical observation of random variation that is composed of different factors and their effects on the use. The smallest adult user proportions are observed in Hospital Districts with more Swedish speaking persons. Adult user proportions were high in rural areas and in areas of high population density. Because only the Prescription Centre is used in the Åland Islands, the language (Swedish) and generally good health of people in the Åland Islands (less e-prescription data) may explain the low adult user proportions of PAEHR.

In Finland and elsewhere, access to a public healthcare provider by phone has been poor because these services have been from time to time overwhelmingly overcrowded. Pressure to increase access to healthcare services may be aided by granting patients an access to view their own patient records, test results or making a non-urgent appointment time in online PAEHRs, instead of trying to request this very information or service via phone. It is also vital that information recorded to the Patient Data Repository is understandable in common language and contain clearly formatted guidance for patients and/or their caregivers for them to take responsibility themselves on their own care. Since physicians and nurses are well acquainted with the Finnish

national PAEHR, have used it by themselves, and know how to give patient guidance on using it for various purposes, there are good preconditions for enhanced overall patient guidance for better care.

Since the beginning of 2017, all healthcare providers in Finland are obliged to introduce the e-prescription system [35]. Community pharmacy customers are familiar and very satisfied with the national e-health service for viewing their e-prescriptions [36,37]. General practitioners in Finland report that e-prescribing has improved their patient medication management [38,39]. Finnish health professionals have positive expectations about the new PAEHR [40]. Similar results have been reported in other Nordic countries, such as Sweden [8,28–31,41] and Denmark [2,4].

Future research is certainly needed. It is of utmost importance that we generate more in-depth data and knowledge about the PAEHR users and follow the trends in use in future. Another issue is to find out characteristics, those of the users and those of the municipalities in order to explain use or no-use of the national services. In addition, it would be interesting to compare access to patients' data in the PAEHR and the data in the Patient Data Repository and the Prescription Centre, too.

Horizons for productivity leaps and empowering patients to participate in self-care services provided by online PAEHRs are encouraging and potentially extensive. However, reaching these goals essentially requires redesigning service provision processes that are formed over centuries, and also strong, well planned and executed change management. Support and motivation provided by healthcare professionals may have significant impacts on willingness and capabilities of the patients to start to use and using online healthcare services. In future, social and healthcare professionals have to rely on the fact that patients are increasingly capable to manage their personal health information. In addition, professionals should deepen their understanding on effects that patient participation experience may have for successful care.

Conclusion

In conclusion, two out of three adults by end-2018 and almost half of the adults in 2018 used the Finnish national, state financed patient accessible electronic health record that was launched in 2010. User proportions varied between Primary Healthcare Centres, Hospital Districts and University Hospital Catchment Areas. We observed that the smaller the regional area analyzed, the bigger the variation in proportion of adult users.

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Acknowledgements

We thank Ms Marina Lindgren, Director of Information Services and her staff at the Finnish Social Insurance Institution (Kela) for indicator data.

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