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Patient Access to Electronic Health Records:
Differences Across Ten Countries

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Title Page

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Abstract

Objectives: Patient-accessible electronic health records (PAEHRs) are being implemented at international scale. Comparing policies and systems could allow countries to learn from each other to address global and nation-specific challenges. We compare national PAEHR policy (hard and soft regulation) and services in 10 countries.

Methods: PAEHR policy and system documentation was gathered from Australia, Denmark, Estonia, Finland, France, the Netherlands, New Zealand, Norway, Sweden and the United States. A basic analytic model for policy analysis was used to delimit our focus to policy content, followed by an inductive thematic analysis across countries, in which we clustered initial themes into a set of categories of PAEHR service "approaches" related to three specific content areas.

Results: Although all 10 countries ensured some patient rights to access medical records, policies and systems were highly variable, as were the technological processes arising from these. In particular, three policy areas showed great variability. Depending upon country of origin, a patient would encounter differences in: login procedures (security), access to own and other patients' data during adolescence (user rights), and types of medical data made available to the patient (data sets).

Conclusions: Individuals encounter very different access rights to their health data depending on where they live. Countries may be able to develop improved policies by examining how other nations have solved common problems. Harmonizing policies is also an initial step likely to be needed before cross-national PAEHRs could be possible.

INTRODUCTION

Technological advances, patient movements, and national policies are driving efforts to implement patient accessible electronic health records (PAEHRs),[1] that is, e-services providing patients with the possibility to *continuously*, rather than upon request, "view, and sometimes edit or comment, on their electronic health record" via the Internet [2:2]. PAEHRs may be provided through various systems, such as Personal Health Records controlled or maintained by patients, and patient portals typically maintained by healthcare or technology providers. Today there is a growing body of research about PAEHRs, including studies demonstrating that PAEHRs may contribute to patient empowerment, time-savings, and quality of care as well as studies underlining the numerous challenges involved in reaching such outcomes.[1-18] The current literature in this domain however generally focuses on single implementations of particular PAEHR services, or the state of affairs in a particular country. This is problematic as cross-national perspectives are likely to become increasingly important.

For one, globalization is contributing to international migration and to patients becoming increasingly mobile/"global"[19], creating new needs for patient safety, access to data and continuity of medical care across national borders.[20] As we will show, such continuity of access is today even difficult *within* countries. Further, technological advancements such as cloud services present states, care providers and patients with new possibilities to store and access data in disparate geographical locations, which creates a need for countries to become more aware of foreign laws and the jurisdictions their data may travel through or be stored in.[21, 22.] Along with such developments challenges related to data ownership will also emerge. Finally, the European (EU) General Data Protection Regulation (GDPR[23]) comes into force in May 2018. Applicable to the entire EU, the GDPR will lead to stricter requirements on the handling of personal data. The Regulation will have a considerable impact on all organizations based in the EU that process personal data, but also on organizations based outside of Europe providing services to the European market.[23]Cross-national comparisons are hence of interest within countries currently developing or improving their PAEHR access policies, as such comparisons may inform the development of policies.

Although policy and regulations have been acknowledged to be foundational to PAEHR development,[24] there have been few attempts to compare national policies and their manifestations into PAEHR services internationally. The aim of this study is to compare national PAEHR policy content [25] and PAEHR services in ten countries and to discuss the implications of these differences, from a patient perspective. We focus on three areas: patient login procedures, parental and self-access during adolescence, and data sets displayed to patients.

METHOD

This study stems from an international network of individuals engaged in the development, regulation, or study of PAEHRs. Our criterion for including countries was the implementation of one or more PAEHR services in parts or across the entire nation in 2016. We excluded countries with only strategies pointing towards national use of PAEHRs but with no actual implementation of a solution. The ten participating countries represent the *Nordic countries* (Finland (FI), Norway (NO), Denmark (DK), Sweden (SE)), *European countries* (Estonia (EE), France (FR), the Netherlands (NL)) and *non-European countries* (Australia (AU), New Zealand (NZ), United States (US)). Table 1 outlines the health system structure (see [26] for a more comprehensive overview), and the state of the PAEHR development and use in each country, as at December 2016. Data about PAEHR usage should be interpreted with caution, as only fragmented data was available at the time of the study.

Guiding frameworks and definitions

PAEHR services. By PAEHR, we mean the service provided by an online system granting patients continuous access to personal medical health data from electronic health records (EHRs) or other health IT systems. The definition of PAEHR encompasses personal health records (PHRs), and patient portals. Although PHRs and patient portals may include administrative and communication functions in addition to data access, our paper focuses only on medical record access.[1-2]

PAEHR regulation. We initially approached the ten different national policy contexts based on a basic analytic model for policy analysis[25] that distinguishes between policy content, policy process, and policy context. This study focused on policy *content*: actual regulation and distributional impact (who and what is regulated). [25] We limited our focus to national policy developed by government, governmental agencies and standard setting bodies. We further distinguished between "soft" and "hard" regulation. While there is no easy dividing line between 'soft' and 'hard' regulation, we defined *hard law* as national legislation that is mandatory and absolute (also referred to as binding or rule-based governance) and *soft law* as alternative forms of governance, which are conditional or voluntary. Soft law refers to rules that are not legally binding, for example, recommendations, agreements, national action plans, or policy documents. Soft law entails normative commitment and may have political effects[38-41]. This implies that soft law shall be considered politically binding rather than legally binding. While soft law is sometimes referred to broadly as regulation that relies on open-ended processes such as benchmarking and peer group audit, we only included national *written* recommendations.

Data generation

Documentation constitutes the primary source of data in the study. Based on the guiding definitions above, participating researchers gathered documents in their respective country describing hard and soft law relating to EHRs, patient access to EHRs/medical data, and implemented PAEHR systems per the first and second quarter (Q1-Q2) 2016. Documents included healthcare legislation, national open data strategies and e-Health reports, technology and e-service standards, and PAEHR system descriptions, and PAEHR diffusion and usage statistics about each country. Field-work including participant observations, participation at health IT conferences, informal conversations and interviews with patients and professionals using PAEHRs performed by the authors in previous studies provided background information and facilitated the gathering of relevant documentation. Selected parts of the vast amounts of information gathered about each country were translated by the authors in each country, and sorted in terms of a table with separate columns for hard and soft law in each country respectively, and rows representing the target of the regulation (age, use, access procedures, etc.). Each author filled in the table, which was continuously double-checked and revised by the first author. New rows were continuously added based on the new regulative areas and PAEHR service features that were identified. Work on the table content was iterated between all the authors and updates were communicated until 2016 Q2. Subsequent changes in regulations or PAEHR services were not included.

Data analysis

Data analysis occurred in parallel with data generation. Several tables and mappings were created to facilitate familiarization with the data of all participants and to make sense of cross-national differences, leading to follow-up questions to and extended document searches by each participant. Inspired by thematic analysis as outlined by Braun and Clarke[42], the first and second author then identified three content areas characterized by cross-national differences with significant impact on the usability of PAEHRs from a patient perspective: regulations concerning 1) patient login procedures, 2) parental and self-access rights during adolescence, and 3) data sets visible to patients. The first author performed an inductive thematic analysis[42] of data, pertaining to the three areas, in order to identify patterns in the regulatory and PAEHR service "approaches" taken by the countries. An initial coding of the data relating to the areas in each country was performed, where data extracts describing regulations and PAEHR systems in each area were labeled with a few describing terms. A cross-country analysis was then performed, comparing initial codes from all countries and combining them into themes. The themes were later aggregated into categories of regulatory and PAEHR system approaches as

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presented in the findings section below. Several rounds of review were conducted in which coauthors examined the interim themes and approaches and provided corrections and feedback.

Note that while we base our analyses on vast amounts of documentation, extensive field-level engagement and personal experience from the development in each country, systematic data was lacking in several areas. This left us with the possibility to identify important aspects, and to illustrate tendencies, variability and challenges rather than an accurate map of the status in each country.

RESULTS

Patients in all the studied countries had the legal right (as specified in hard law) to access their health data upon request. There were however national differences regarding whether or not continuous, *electronic* access was specified in this legally ensured right. We identified three overall regulative approaches to PAEHRs in the different countries. The choice of paper-based or electronic patient access channel was specified in soft law and/or delegated to regional governments or care providers in a majority of countries (AU, DK, FI, FR, NL, NO, NZ, SE); we refer to this as the "*decentralized approach*". In contrast, Estonia used the "*mandatory national approach*", with hard law obliging care providers to display data via the national service platform,[43-45] and the US implemented a mandatory "*financial incentives approach*", specifying in hard law that healthcare organizations seeking federal incentives for electronic health records (EHRs) were obliged to provide patients with copies of their electronic records upon request (the HITECH Act of 2009 and the subsequent federal rules operationalized this act as part of the "Meaningful Use" program in the US; exceptions meant that not every doctor or hospital was covered by the mandate).[46-48] The governmental eHealth strategies emphasized (via soft law) the desirability of providing citizens and patients with continuous, electronic access to their health data in all the countries.[49-54] Further, the number of implemented PAEHR systems in each nation ranged from one (DK, EE, FI, FR), to two (SE, NO – both countries however plan to merge into one national service in 2017-18), to three or more (AU, US, NL, NZ).

PAEHR login procedures

In all the studied countries, national legislation mandated "secure" protection of and patient access to medical data, even though in many cases the legislation did not specify if this concerned paper-based or electronic data, and did not specify the exact solution for achieving secure access. In this section, we discuss one of the most salient privacy and security implications from the point of view of the patient, which is how the patient would access a PAEHR.

We could distinguish three approaches in the attempts to achieve the aimed for "secure access" stated

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in national legislation among the countries. We refer to the first approach as "*one service - one login,*" enabling

patients to access data from different care providers via *one* interface to a single PAEHR system. This pattern

was evident in most countries with one available PAEHR system (DK, EE, FI, FR). In EE, FI and DK, there was

a national established login solution that citizens used to access the PAEHR system as well as other e-

government services. France used a PAEHR-specific login procedure. Table 2 provides examples of login

procedures applied in countries with the one-service-one-login approach.

---Insert Table 2 about here---.

We refer to the second pattern as: "*Multiple services – same login*". This pattern was evident in

Sweden and Norway where there were two available PAEHR services at the time of the study, although there

was an explicit aim to merge them into one. The two PAEHR services used the same login procedure, but users

receiving care in different regions tied to different PAEHR services were forced to separately login to each of the

services. This was because data could not be transferred between the two services at the time of the study.

This problem was even more serious in countries where there were many different (>2) PAEHR

services (AU, NL, NZ, US), which required different login procedures. We refer to this pattern as "*multiple

services - multiple logins*". Table 3 illustrates some examples of the variation in "multiple services – multiple

login" procedures. In the US, an important barrier to single login system was the national prohibition (hard law)

on a unique national medical identifier for patients, enacted by Congress as part of the HIPAA privacy and

security regulation.[48] Medical organizations assigned unique medical record numbers to their patients, but the

lack of a national identifier made it difficult to unambiguously identify the same patient across different medical

organizations, which remained a barrier to medical record interoperability.

--Insert Table 3 here---

Figure 1 provides a visualization of the different patterns identified.

Insert figure 1 about here--

Parental and self-access rights during adolescence

National laws stated at what age individuals were eligible for self-access to their medical data

(without specifying if this concerned paper-based or electronic data) in all countries except France and Finland.

Individuals were legally eligible for self-access at different ages ranging from: >12 (NL)[64], >14 years (DK)[65],

>15 years (NO[66], EE[45]), and 18 and older (AU[67], NZ [68-70], SE[71], US (with some variation by state law[72])).

National laws also specified the ages when parents were entitled to access data about their children. For instance,

in Australia, Estonia, France, and Sweden, parents or guardians were entitled control over a minor's (<18 years)

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healthcare, including access to the child's records. In the other countries, parents had the right to *request* access to the health data of their children (with the exception of parents under suspicion of abuse). Ages for this varied across the countries, at the child's age of <10 years (FI [73-75]), <12 years (NL[61, 76], NO[66]), <13 years (NZ[68-70]), <18 years (DK[65]).

There were overlaps as well as gaps between the right to parental and self-access to data during *adolescence*. That is, the years between the age at which the individual was considered a "child" and at which parent access was entitled on the one hand, and when the individual was considered an "adult" and entitled self-access, on the other hand. National legislations were not explicit regarding access rights during these years. Instead, how to treat adolescent citizens was typically discussed in policies and guiding manuals (soft law). However, such recommendations were typically generally stated, leaving room for variable interpretations of how to implement them.

Given the ambiguity regarding access rights during adolescence in the prevailing hard and soft regulations, the fragmented and variable way in which these rights were operationalized in available PAEHR services is not surprising. We identified three categories of approaches among the countries here. Table 4 provides examples of the access approaches exhibited by the countries.

Insert Table 4 here—

The "*default parent access*" approach prevailed in France and Estonia. In both countries, the national PAEHR service granted parents access to their child's health data until the age of 18 per default. Exceptions were however possible, as exemplified in Table 4.

The "*default blocked access*" approach prevailed in Norway and Sweden, where *neither* the child nor the parents had access to data during adolescence per default. Attempts to create an automatic procedure for allowing both parental and self-access during adolescence were discussed.

The "*default double access*" approach was used in Finland, where simultaneous parental and self-access was possible during parts of the years of adolescence, conditioned on parental approval.

Finally, in Australia, Denmark, the Netherlands and New Zealand, the PAEHR policies did not technologically prohibit or order access at certain ages per default but rather allowed flexibility for the healthcare providers to solve access issues at local level, on a *case-by-case* basis, as illustrated in Table 4. In the US, all three approaches were found.[72,79]

Figure 2 provides a visualization of the four patterns identified.

Insert figure 2 about here--

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Data sets displayed to patients

The legislation (hard law) in all countries stated that citizens had the right to access all health data about themselves (without specifying if this concerned paper-based or electronic data). [45-46, 65-67, 70-71, 75-76, 80] This was operationalized differently in standards/recommendations (soft law) and implemented variably in PAEHR services and systems. Access to historical data takes on a new meaning in the e-context as electronic data may not be available, for instance, in an unlimited period back in time. We identified two patterns in the regulation of and implementation of PAEHRs here. Only Estonia had a "*national standard*" approach, with its specification of the date (January 2009) from which patients were to have access to their data.[43-45] In most countries, it was up to the regional government or healthcare provider to decide to what extent historical data was to be displayed (AU, DK, NO, NL, NZ, FI, FR, SE, US), a pattern that we labeled "*locally decided.*" While there was variability across regions and care providers in countries exhibiting this pattern, it generally meant that PAEHRs displayed data from the date at which the organization implemented its EHR or PAEHR system. Patients seeking older data usually had to file a request for a copy of it, and get it on paper.

What kinds of *data sets* then, were made visible to patients? An observation across the countries was that PAEHRs only provided access to a limited selection of the wide range of structured and unstructured (non-numerical, free-text or image) data that could in theory be made available to patients. Beyond this common characteristic among all the PAEHRs in all countries, we identified two different overall approaches. Estonia, the US and France adopted an "*mandatory display*" approach, explicitly mandating care providers to share certain sets of data with patients through PAEHRs in hard law. Some data sets however remained voluntary. Other countries had implemented either national and/or regional regulations, in terms of soft law. This resulted, in technological terms, in either a *"nationally enabled display"* or an "*opt in/locally enabled display*" approach, with prevailing regulations leaving discretion to regional counties, care providers or sometimes even individual physicians regarding which data sets may be displayed to patients.

Table 5 below provides an illustration of the variability in the data sets made visible to patients by PAEHRs, and how data display was regulated, in the different countries. Note that the table is based on each author's review of the services available in their country. The table does not provide a complete map of the data sets or functionality that may be enabled by all available solutions at all locations. The purpose of the table is to illustrate the major patterns in each country. As shown in the table, some data sets were voluntary in countries using a mandatory approach at overall level, and some data sets were required in countries using an enabled approach at overall level.

---Insert Table 5 about here---

As illustrated in Table 5, some countries (FI, FR, EE, DK) had implemented one, mandated, national PAEHR service that displayed, or legally required the display of, a relatively large number of data sets, using a *"nationally enabled display"* or "*mandatory display*" approach. Other countries (AU, NZ, NL, SE) instead exhibited a relatively large number of data sets that were enabled but not mandated using an "*opt-in/locally enabled display*" approach. Due to the lack of comparable data available about the extent to which the *mandatory*, *nationally enabled or locally enabled* data sets were *actually* displayed to patients in each country, it is difficult to "rank" the countries based on the degree to which they made medical data available to patients. The insight emerging from the fragmented data about access/use in each country (see Table 1) was rather that none of the approaches guaranteed patient access. The "opt-in display" approach quite expectedly generated great variability in the data displayed to patients living in different regions, served by different care providers or even connected to different individual physicians. However, countries using the *mandatory display* or *nationally enabled display* approach also exhibited variation in cases where the PAEHR services implemented built on the willingness of health professionals to, document their actions, manually populate the PAEHR with data, or to "activate" data features, resulting in PAEHRs being partly or completely "empty", as some or all data sets, that were legally required, were actually being withheld from patients, as is currently the case in France, for instance.

Discussion

Individuals in the 10 studied countries faced extremely different access rights to their medical data depending on where they live and where they seek care. Although regulation in all the studied countries in this study ensured residents' rights to their health data, the details varied of how data was accessed, what data was available, from when it was available, and in whether full electronic access was supported by hard law or soft law. This policy diversity raises the possibility that countries may be able to develop new and/or improved policies by examining how other nations have solved common problems and whether hard or soft law underpinned them.

We identified three overall regulative approaches to PAEHRs among the countries: the "*decentralized approach*" (generally underpinned by soft law), the "*mandatory national approach*" (generally underpinned by hard law), and the "*financial incentives approach*" (a mix of hard and soft law). Within these overall approaches, there were numerous differences in how the countries regulated and implemented PAEHRs. Below, we will discuss the implications of the identified approaches pertaining to login procedures, parental and self-access during adolescence, and data sets displayed, from a patient perspective.

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Patient implications of the identified login procedure approaches

Regarding the differences in login procedures, we identified the approaches: "*one service-one login*", "*multiple services – single login*", and "*multiple services - multiple logins*". To illustrate the implications of these approaches, consider the fictive situation of a woman named Christina. If she lived in Denmark (representing the one system-one login approach), she would encounter the single online sign-on PAEHR that would allow her access to all data made available to her by any provider throughout the country. Were she instead a citizen in the US (with the multiple systems-multiple login approach), she would encounter her health data scattered across many different healthcare organizations. For example, she might have a pediatrician at one healthcare organization, and a gynecologist at another healthcare organization, each one of which could require a unique login to its unique PAEHR. As a result, Christina would need to go through multiple authentication procedures to access all her health data. Furthermore, there is no guarantee that she could aggregate it herself, so she might end up simply browsing three different systems every time she needed information, or downloading different copies of her records. Given these difficulties that could occur within a country, it is easy to imagine the difficulties Christina would have if she moved to a new country and needed to simultaneously access data held in PAEHRs provided in different countries.

Patient implications of the identified approaches to parental and self-access rights during adolescence

Our results demonstrate variable age restrictions and a common ambiguity in hard and soft law regarding user rights, specifically regarding parental and self-access during adolescence. We identified four approaches among the countries: the *default parent access*, the *default blocked access*, the *double access*, and the *case-by-case* approach.

Returning to Christina's situation, consider the hypothetical situation of her having a 15-year-old, chronically ill son named Paul. Let's assume that Christina had monitored Paul's health development since his birth as closely as possible, through all paper-based and electronic health data available to her. If Christina were a citizen in France (representing the default parent access approach), parts of Paul's health data would per default be available to her through her PAEHR until he was 18, thus enabling her to continue to be actively involved in monitoring his health. This approach however reduces Paul's opportunities to begin managing his own health as a teenager. In contrast, in Sweden (representing the default blocked access approach), neither Christina nor Paul would have access to Paul's data from the age of 13, unless a case-by-case solution would be implemented. Further, Christina's access opportunities as a US citizen and facing the case-by-case approach would be difficult to predict. She would have to deal with several different healthcare organizations, each one of

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which could provide different parental access rights. She may suddenly lose access to some of Paul's data, while keeping access to other data. The latter two approaches could hence imply a significant disruption in the health management routine of Christina and/or Paul. If Christina and Paul were to temporarily move abroad, the possibilities for obtaining a coherent record of Paul's medical data online would be even more limited.

Patient implications of the identified approaches to data displayed to patients

Regarding data sets made visible to patients, we identified two approaches: the "*mandatory display*" and "*opt in display*" approach. None of the available PAEHR solutions however achieved full transparency of a person's health information.

Consider Christina again. No matter where she lived, she would only be able to access a sub-set of the data that could in theory be made available. Further, in none of the countries would she be able to view longitudinal data covering her (or Paul's) health back in time online. For instance, it would be impossible for her to analyze and compare patterns in her own and her son's health development during the last 15 years through her PAEHRs. Given that different providers may use different terminology it would further be difficult for her to juxtapose data from different PAEHR systems from the last year. This would impede her and Paul's sense of control and independence, and impede their opportunities to ask for second opinion. The variation in terminology and data sets displayed differ even more between countries, which suggests that merging data sets from PAEHRs from different countries into a single view or record would be very challenging for Christina and Paul. The lack of an agreed and adhered to taxonomy for terms and definitions means that for the current future, a single view of information travelling across multiple jurisdictions will be a complicated, if not impossible undertaking.

Practical implications for technology and policy development

Our results show that several aspects of the observed PAEHR approaches present patients with problems. For one, the multiple login procedures patients need to go through in many countries point to the need to *facilitate interoperability between systems*. We are aware that advances are being made at national level regarding technological, semantic, organizational and legal interoperability, through various national collaborative and interdisciplinary approaches to ensure interoperability between diverse EHRs. [62] However, the heterogeneity in policy illustrated here suggests that extended efforts to improve legal interoperability at international level are particularly needed. The European GDPR will lead to harmonization in some respects, but additional initiatives to encourage cross-national agendas within and beyond the EU are warranted. Indeed, a cultural shift is needed here, from the current somewhat myopic and competitive mindset in which countries typically aim to "become

the best e-health nation in the world", to shared ambitions to create safe access to medical data across countries and jurisdictions for tomorrows' citizens. Collaborative spaces are needed in order to facilitate the creation and dissemination of international rather than national goals, strategies and evaluation practices. Such a development could accelerate global innovation in e-health and it would be strengthened by e.g. comparison of existing national health information exchange (HIE) platforms and service contracts.

In addition, the uncertainty and variability in parental and self-access rights during adolescence point at a need to *develop ways to reduce the amount of manual work and risks associated with case-by-case judgement* of the "maturity" of young individuals and the potential inappropriateness of allowing their parents' access. In order to reduce the risk for unequal rights among patients as well as administrative and moral burden on professionals that current case-by-case approaches imply, the sharing of "cases" may be relevant. E-platforms enabling international knowledge exchange about how cases have been handled nationally or locally could be a way to learn from "exceptions" as they emerge, and to turn this into learning experiences. As all countries struggle with how to balance the need for individualized, situated judgement in unpredictable situations and in relation to emergent needs on the one hand, and fairness, predictability, and consistency in patient access on the other, international discussions about the pros and cons related to different solutions, and perhaps the development of shared feasible principles (rather than detailed standards) is worth considering.

Finally, the limited sets of data that are displayed suggest that neither mandatory nor opt in approaches can guarantee patient access; provider adherence to policy is a key issue in all the countries in this context. Countries that use PAEHR systems that build on the manual efforts of individual physicians to populate PAEHRs however seem to exhibit more variability than countries with PAEHR systems that involve automatic data transfer from EHRs to PAEHRs. In all countries, there is a need to develop implementation approaches encouraging and facilitating a systematic engagement in expanding the data displayed in PAEHRs by healthcare professionals. This requires measures beyond technological ones and they are emerging in several countries. For instance, Sweden has forums where healthcare professionals as well as patients can provide input to the development of PAEHR systems, usage routines and regulations[49]. France is looking for ways to push health professionals to populate and use data from the French PAEHRs in their day-to-day work in the national policy. In the US, the Open Notes project has successfully demonstrated that opening the entire record to the patient (including free-text narrative written by doctors) is welcomed by patients and generally acceptable to doctors as well.[81] At general level, a growing political will to provide complete access is discernible in most countries and we expect that expanded efforts will be made to ensure that all patients have access to all medical data

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immediately. Until this ambition is reached, we encourage countries to make visible what data sets are *withdrawn* from patients. This, too, would imply increased transparency.

Overall, given the different histories and institutional contexts of the countries, we do not expect or recommend a one-size-fits-all solution to these issues. We do however suggest that countries take the opportunity to exchange experiences and look at solutions tested in other countries. The long-term goal is an international interchange between national health information exchange infrastructures, on all levels of interoperability. Until then, minimal requirements may be defined through international interdisciplinary networks including patient and family advisors, standardization bodies, professional peer-to-peer forums, or through certifications of technological solutions.

Conclusion

While there is a large pool of literature focusing on the potential benefits of existing PAEHR services provided by specific providers, or in certain countries, few attempts have been made to raise the discussion about PAEHR to an international policy level. This study set out to compare national PAEHR regulations and services in 10 countries. The results show that a mix of hard and soft regulations and a diverse set of approaches to specific issues prevail in all countries, which have simultaneously enabled and restricted a consistent and meaningful development of systems towards increased patient access to their own medical data. Importantly, the multiple different patterns reveal great variability regarding how access in three (security, user rights, data sets displayed) different areas is operationalized within and across countries. This in turn implies that accessibility is fragmented and unequally distributed nationally and internationally and so may actually be contributing to further inequity rather than creating greater patient empowerment. We conclude that policy development and cross-country learning is particularly needed in the following areas: extended efforts to improve international interoperability at a legal level, as well as joint efforts to handle adolescent dilemmas, and variability in data sets displayed. In order to facilitate evidence-based policy development, more research is warranted about how actors have succeeded or failed in solving these issues. We hope this study will spur more international initiatives that contribute to the development of international PAEHR visions and agendas. Such visions are needed in order to provide a long-term direction for the innovation of technologies, services and processes across nations.

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Figures

Figure 1.
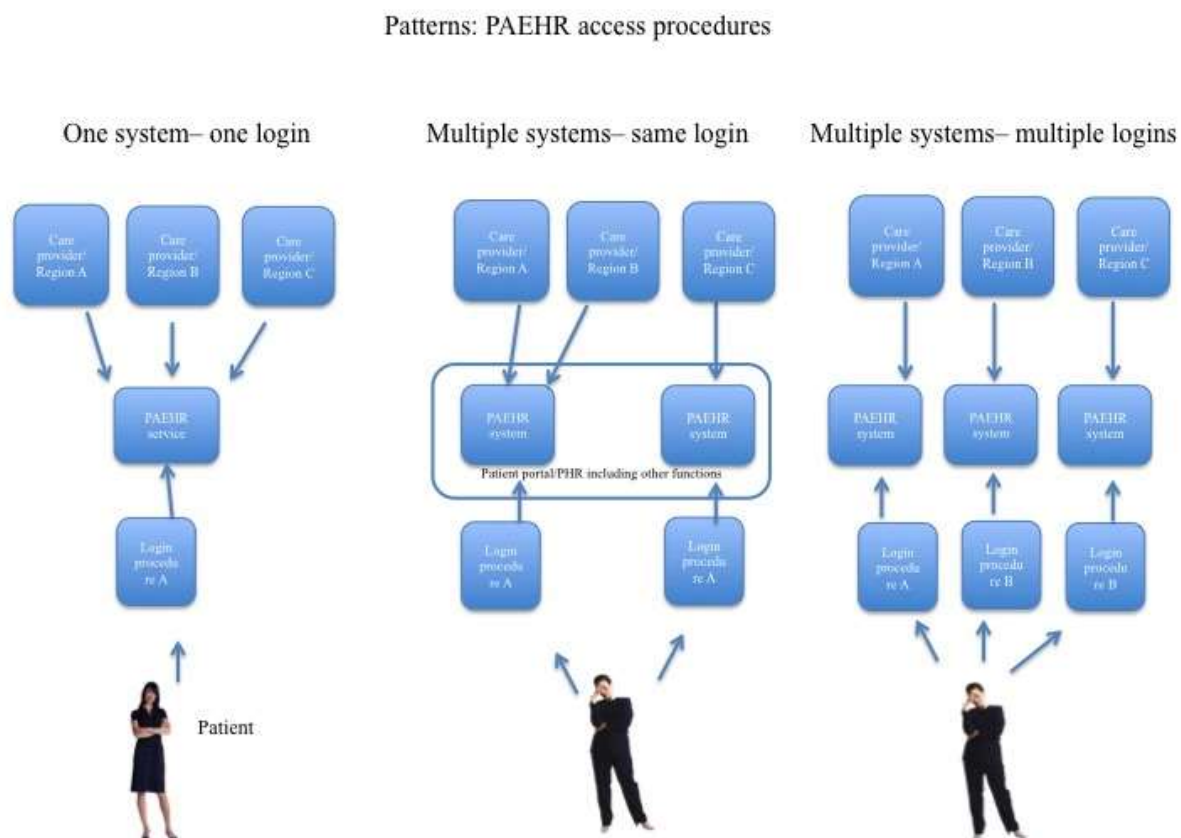

Patterns: PAEHR access procedures

Figure 1. One service – one login: all care providers in all regions were connected to the same PAEHR service. Multiple services – same (but repeated) login: care providers in different regions could choose to connect to one of two PAEHR services. Each of the PAEHR services was populated with data from some but not all providers. Data could not be transferred between the two services. Multiple services –multiple different logins: care providers could choose among several different PAEHR services. Each PAEHR service was populated only with data from one or a few among several providers. Patients accessed the different services through different, provider-/service-specific login procedures.

Figure 2. Different ways in which PAEHR solutions have operationalized parental and adolescent access rights.

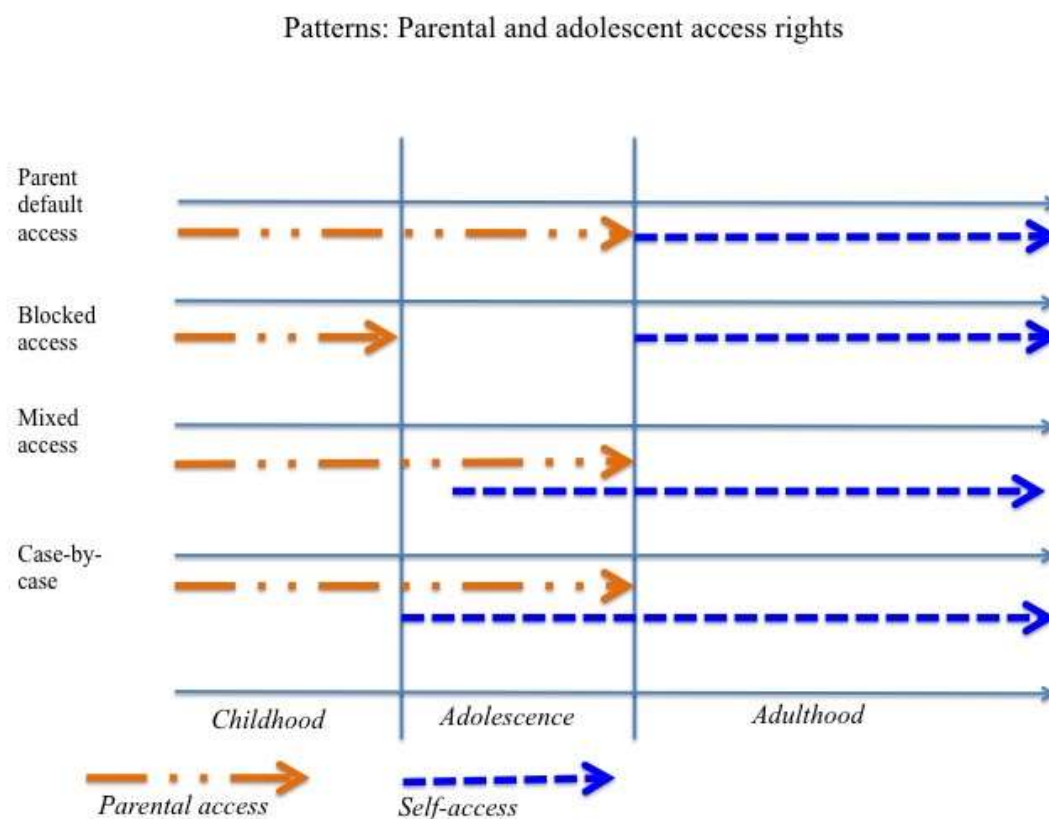Patterns: Parental and adolescent access rights

Figure 2. Different ways in which PAEHR solutions have operationalized parental and adolescent access rights.

See Table 4 for list of countries using each approach.

Table 1. *Overview of health system structure and PAEHR status in the 10 studied countries (December 2016).*

Country*	SE	NO	DK	FI	EE	FR	NL	AU	NZ	US
Healthcare system financing and provision	Tax-funded. Regional and municipal governments are responsible for provision of care and may contract	Tax-funded. Regional and municipal governments are responsible for provision of care and may contract	Tax-funded. Regional and municipal governments. are responsible for provision of care and may contract	Tax-funded. Responsibility for providing healthcare is held by state and municipalities who may	Mandatory health insurance (earmarked social payroll tax). Gov. finances emergency care for uninsure	Mix of: 1) mandatory public basic insurance (tax-funded), and 2) complementary, private insurance (mandat	Mandatory private insurance. Private care providers deliver care. Supervision of health system is conduct	National health insurance scheme. There is a cap on individual annual expenditure after which services are free.	Tax funded health care. District Health Boards responsible for hospital care. Primary care a mix of public (tax)	Public and private insurance plans contract private physicians and hospitals. Insured patients pay non-covered

	SE	NO	DK	FI	EE	FR	NL	AU	NZ	US
	public and private providers.	public and private providers	public and private providers.	contract public and private providers.	d, ambulance services, and public health programs.	ory, paid by the individual).	ed through independent bodies.		funded and user co-payment.	costs out-of-pocket. 8-9% of the population uninsured.
Inhabitants (M=millions)	10 M	5 M	5,6 M	5,5 M	1,3 M	66.99 M	17 M	24 M	4.471 M	320 M
Approximate use of PAEHRs according to available data in 2016*.	0, 8 M users of PAEHRs, 3,4 M (34%) users of national portal.[27]	Core record available for everybody. Data on PAEHR users unavailable, 1 solution had more than 1500 logins/day.[28]	0,22 M *logged into* the site through which PAEHR was provided in Jan 2016. 1.9 M had *visited* the portal within the last 12 months.[29]	0,75 M logins per month and 0,375 M user per month.[30]	>0,26 M users, 20% of population.[31]	0,597 3 M[32]	10% of the chronically ill had online access to their records in 2015.[33]	At March 2016, 0,1 M people were registered for a PAEHR.[34]	420 of 1029 primary care practices offered a portal. At December 2016, 0,24 M adults were registered for a portal.[35]	Uncertain. A 2013 survey: 33% of Americans *had been offered* a PAEHR.[36]. A 2015 survey in NYS**: 27% of state residents had *used* a portal[37]

*SE= Sweden, NO=Norway, DK=Denmark, FI=Finland, EE=Estonia, FR=France, NL=Netherlands,

AU=Australia, NZ= New Zealand, US=United States of America.

** New York State

Table 2. *Examples of the "One-service-one-login" patient login approach (Dec. 2016).*

Country, national PAEHR service	Login procedure used to access the national service.
FI, national PAEHR service available via Kanta.fi portal.	Multi-factor authentication (MFA), requiring several separate pieces of evidence to an authentication mechanism. Three ways of authentication available: 1) Mobile authentication. 2) Online bank identifiers, based on onetime list of passwords used with personal BankID. 3) A certificate card with an embedded chip containing a Citizen Certificate.[55]
EE, national PAEHR service available via https://www.digilugu.ee	Multi-factor authentication (MFA). A two level identification including password and some physical measure (ID card, mobile-ID, RF-ID, etc.). Required digital authentication and signing via the Public Key

portal.	Infrastructure (PKI) provided by the state.[45]
DK, national PAEHR service available via sundhed.dk portal.	Multi-factor authentication (MFA), NemID, a secure shared login system based on the Public Key Infrastructure (PKI), which was built upon encryption, digital signature, electronic certificates, and certification centers. Users needed a user ID, password, and a code from a "code card" to log into any system that supports NemID.[56]
FR, national PAEHR service available via https://www.mon-dmp.fr/fr/.	Multi-factor authentication (MFA). Login procedures, including password and SMS code, specific to the national PAEHR service, including password and SMS code.[57] Patients could not use the PAEHR password and code to access other e-government services.

* DK=Denmark, FI=Finland, EE=Estonia, FR=France.

Table 3. *Examples of the "multiple services- multiple login" patient login approach.*

Country*	Multiple services – multiple login procedures
AU	One factor authentication. Patients used a static username and password arrangement for access to their PAEHR. Different username and password arrangements were however necessary to access different kinds of data. The Medicare number for access to data about medications and health services use was not allowed by law to be used to identify or link individual records across different services. [58-59]
NL	Some organizations/PAEHRs required users to login via DigID (Digital Identity), an online identification method used for other e-government services.[67] Other organizations/PAEHRs required DigID in combination with SMS. Yet other organizations/PAEHRs applied individually developed login procedures.[60-61]
NZ	One factor authentication. Access through a patient portal where patients used a unique static username and password, that was prompted for change three times a year.[62]
US	Healthcare provider organizations authenticated patients to establish an account on their portal in several different ways. For example, some required patients to come in person with forms of identification in order to establish an account. Others required patients to answer authentication questions online that were drawn from public records databases of property ownership, car registration, etc. After the patient had been authenticated and an account was established, login usually required a static username and password.[63]

*NL=Netherlands, AU=Australia, NZ= New Zealand, US=United States of America.

Table 4. *Examples of the different approaches to parental and self-access rights during adolescence in the countries.*

Country*	Access approach
Default parent access	
EE	Parents had access to their child´s medical data through the national PAEHR service until the age of 18 per default. An underage patient could in theory close or restrict access to any person, including parents, using the login procedure. The lower limit of the age when underage patients could close their data was not defined.[45]
FR	PAEHR self-access required a National Social Security Number (NIR). Only adults had a NIR. Hence, minors < 18 were not eligible to create their own PAEHR due to their lack of NIR. The health data of minor patients were stored in the PAEHR of one of their parents. Health professionals

could however involve the minor in the decision of authorizing or preventing parental access to some of the minor's health data, this depended on the perceived maturity of the minor (soft law).[77-78]

	Default blocked access
NO	Both PAEHRs in Norway offered access to all patients above 16 and parents of children under the age of 12; however, there was no standard access procedure for patients between 12 and 16.
SE	The national regulatory framework (soft law) stated that parents were entitled access to their child's health data from 0 to 12 years, while self-access was entitled from 18 years. From 13 to 17 years, both parents and the adolescent were per default excluded from immediate access in both of the available PAEHRs.[49]
	Default mixed access
FI	Parents possessed the right to access health data related to their child per default at the age of <10 but were per default excluded when the child got older. Children in Finland could access their PAEHR by identifying themselves through secure means. If parents did not approve the electronic ID card for their child, the child's health data was not accessible via Internet. The child/parents were then forced to make a request by asking the healthcare provider for a (paper) copy.[73-75]
	Case-by-case approach
AU, NL	Access solved differently across providers. Anecdotal observations from AU suggested that access may have occasionally been given to 14-17 year olds while at other times not. There was however a general recognition in AU that parents should get permission from their 14 year-old children to access their Medicare information, while 16 was the legal age of consent. Hence, in AU, the "legal" age of consent and the perceived "moral/ethical" age of consent differed.
US	Access solved differently across providers. On the basis of factors including state laws and local social norms, different healthcare organizations reached different interpretations about ages of access to records. Organizations sometimes granted both adolescent and parents access, or provided access to the adolescent while removing parental access, or cut off all access to both adolescent and parent.[79]
NZ	Access solved differently across providers. Anecdotal observations suggested that access may have occasionally been given to 16-17 year-olds directly, while at other times parents were instead allowed direct access at these ages.

Table 5. Examples of differences in data sets displayed by countries in Dec. 2016. The colors illustrate if the display of each of the data sets was 1) explicitly required and mandatory by law, *or* enabled at a national level ("*required*") (dark green), 2) locally enabled, based on decisions made across regions/care providers/software solutions ("*locally enabled*") (light green), or 3) unavailable in the country (white), at the time of the study.*Health declaration forms refer to self-documented information from patient to health care providers, often used in pre-operative or regular health check-up settings.***SE= Sweden, NO=Norway, DK=Denmark, FI=Finland, EE=Estonia, FR=France, NL=Netherlands, AU=Australia, NZ= New Zealand, US=United States of America.

Data sets/functions	FI	FR	EE	DK	NO	US	AU	NZ	NL	SE	Required by (dark)	Required or locally enabled by (total)
Medications											7	10
Diagnoses/conditions											7	8
Clinical summary											6	10
Laboratory results											6	9
Medication allergies											6	9

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Block record											6	6
Visits (time/date/provider)											5	10
Access logs											5	10
Operative reports											4	8
Immunizations											3	10
Radiology reports											3	9
Pathology results											3	6
Medical notes											2	8
Referrals											2	8
Condition-specific info											2	7
Prof. medical alerts											1	8
Status of referrals											1	7
Health declaration forms*											1	6
Nursing notes											1	5
Maternity care data											1	4
Community care notes											1	3
Psychiatry notes											0	6
Radiology scans											0	5
Other PACS data											0	4
Data types required	16	13	11	11	6	6	3	3	3	1		
Data types locally enabled but not required	6	1	13	12	13	9	4	18	10	17		
Data types required or enabled	22	14	24	23	19	15	7	21	13	18		

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Highlights

- Many countries have policy guaranteeing patient accessible electronic health records (PAEHRs)

- Although all 10 nations included mandate some type of patient access to medical records in general terms, none mandates continuous patient access to complete EHR data

- The 10 studied countries differ regarding access procedures, age restrictions, and other factors

- The current international status implies fragmented and unequal patient access opportunities

- Policy action is needed in areas of interoperability, self-access rights, and data visibility.