Patient access to electronic health records: Differences across ten countries

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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 medical 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