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# Citizens' Access to Their Digital Health Data in Eleven Countries – A Comparative Study

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**Abstract.** Governments around the world are actively promoting citizens electronic access to their health data as one of a number of ways to respond to the challenges of health care delivery in the 21st century. While numerous approaches have been utilized it is evident from cross-country comparisons that there are different conceptualizations of: both the expected and desired roles for citizens in the management of their own health; the benefits that will be delivered by citizen access and how these benefits should be measured and benchmarked over-time. This paper presents comparative analyses of the methods by which citizens are provided with access to their own health data across 11 countries. The paper aims to stimulate debate on electronic citizen access to health data and the challenges of measuring benefit as well as reflection on capacity of different citizens to engage with e-health.

**Keywords.** Health portals, EHR, Self-management

## 1. Introduction

Citizens' electronic access to their own health data has been promoted as one way to respond to the challenges of health care delivery in most developed countries. To date, numerous approaches have been utilized that reveal the different conceptualizations of both the expected and desired roles for citizens in the management of their own health. Understanding and comparing these approaches provides significant insight into levels of access and use of these electronic systems but also highlights challenges around understanding impacts and benefits [1, 2]. In an attempt to explore these issues, we have analyzed

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the methods by which citizens are provided with electronic access to their health data across 11 countries represented by the contributing authors of this paper. The analyses presented do not claim to provide a wholly comprehensive set of all methods used to support citizen access. Rather, it provides a comprehensive sample illustrating a range of key approaches being utilized. This focus on citizen access aims to build on the broader benchmarking exercise recently undertaken by an OECD survey of 7 countries e-health structured into four broadly defined domains around ICT supported care delivery: provider-centric electronic record; patient-centric electronic record; health information exchange; and, tele-health. In the domain of patient centric electronic records (PHRs), the OECD report highlighted a wide range of poorly defined functionalities across the countries studied [2]. This paper also hopes to build momentum for e-health benchmarking exercises like those already initiated in the Nordic countries with a targeted focus on the benefits and impacts evaluation [1]. Finally, it is acknowledged that some Health Maintenance Organizations (HMO's) have developed their own personal health record (PHR) systems for their members to use [3, 4]. There are a number of commercial solutions allowing individual users to gather, store, use, and share health information [5]. In this analysis the focus has been exclusively on national solutions where all citizens of a country are offered electronic access to their health data and basic health services, e.g. prescription renewal or booking.

## **2. Methods**

Through a search of official national government, or national health organizations' web sites, a number of countries offering their citizens access to their personal health related data were identified. Representatives from the relevant countries were identified among IMIA & EFMI contacts or through personal research collaborative networks and invited to contribute by submitting data on their national solutions as presented in table 1. The data from each country has, where possible, been verified by the official national authority. The summary of the table and the discussion has been circulated among all contributors to gather further commentary and to achieve consensus of the conclusions being presented. It is anticipated that this work will now continue into the future and that more detailed analyses will be presented in forthcoming research publications.

## **3. Results**

For each country, Tables 1 and 2 provide comparison across a number of specific categories. The earliest citizen access was 2003 (Denmark) and the most recent is 2015 (Iceland) with most countries giving access around 2012. The hardware requirements are the same for all the countries. All except two countries require citizens to opt-in. All countries have verified identity management with some aligned with banking identity management, others with government, and others from healthcare providers. Table 2 shows what a citizen can do once access has been authorized. Eight countries do not allow citizens to modify or author aspects of their records. Citizens of most of the countries are able to block access to certain information, while in other countries access to certain information is blocked to the citizens. A wide range of functionality is available, listed in the final column and described in the functionalities key below.

**Table 1.** Comparing citizen access coverage, policy and hardware requirements

| Country     | Year started                                     | Coverage   | Opt in or opt out                                   | Login procedure  | Hardware requirements                                |
|-------------|--|--|---|--|--|
| Australia   | 2012   | Whole population   | Opt-in (moving towards opt-out)                     | myGov username + password with security codes sent via SMS   | Any device with internet access                      |
| Canada      | 2012 – full deployment in 2016                   | Whole population of the province Alberta (Myhealth portal)   | Opt in  | Unique personal identifier and password  | PC/Mac, Tablet, Smartphone running a WWW-browser.    |
|             | 2012 – on-going deployment of Healthspace portal | Population of 4 provinces – (Healthspace and myeHealth)  | Opt in  |  |  |
| Denmark     | 2003   | Whole population   | Opt out   | Unique personal ID + user generated password + secure web-ID generated password  | PC/Mac, Tablet, Smartphone running a WWW-browser.    |
| Estonia     | 2010   | Whole population   | Opt out   | Unique personal ID + user generated password and state X-road data exchange infrastructure   | PC/Mac, Tablet, Smartphone running a WWW-browser.    |
| Finland     | 2011   | Whole population (access to functionalities 1-29 via individual local provider available since 2005)   | Opt in (ePrescription),<br>Opt out (all other data) | Banking system log-in (Unique personal identifier + user generated password + secure web-ID generated password) OR mobile ID                       | PC/Mac, Tablet, or Smartphone running a WWW-browser. |
| France      | 2011   | Started in 4 pilot regions, whole population by late 2016  | Opt in  | Unique personal identifier + user generated password + SMS/e-mail one time password  | PC/MAC running a www-browser                         |
| Iceland     | 2015   | Whole population   | N/A   | Unique personal e-Card   | PC/Mac, Tablet, Smartphone running a WWW-browser.    |
| New Zealand | 2008   | Whole population in primary care   | Opt-in  | National Health Identifier + user generated password.  | PC/Mac, Tablet, Smartphone with a WWW-browser        |
| Norway      | 2014   | Whole population has access to citizen portal helsenorge.no (HN), some services are piloted in the regions: Northern (NN), Mid(MN), and Western(WN) Norway | Opt-out   | Accessible from helsenorge.no. Electronic ID (Bank ID), smartcard, usb stick or Bank ID on mobile phone.   | PC/Mac, Tablet, Smartphone running a WWW-browser.    |
| Scotland    | 2010   | Pilot in two primary care practices  | Opt in (patients had to register to use the portal) | Users were issued a secure user name and password by primary care provider. They needed to download a MS Silverlight plug-in to access the portal. | PC/Mac, Tablet, Smartphone running a WWW-browser.    |
| Sweden      | 2012   | Population living in 9 out of 21 county councils (Status Feb 2016)   | Opt in (patients had to register)                   | Electronic identification (Bank ID) on file or mobile; alternatively Unique personal identifier + user generated password + SMS generated password | PC/Mac, Tablet, Smartphone running a WWW-browser.    |

**Table 2.** Comparing citizens' control of access and functionalities

| Country     | Patients editing rights  | Patients control of access  | Functionalities (ref. to list)   |
|-------------|--|---|--|
| Australia   | Partial  | Patients determine what information is accessible   | 2, 3, 4, 5, 9, 10, 11, 12  |
| Canada      | No   | Block access to certain information   | 2-5,8 (Myhealth portal)<br>2-5, 21, 25 (Healthspace and myeHealth)   |
| Denmark     | No   | Block access to certain information   | 2-4, 6-9, 12, 15-19  |
| Estonia     | No   | Block access to certain information   | 2, 3, 5, 9-15, 18, 21  |
| Finland     | No   | Block access to certain information   | 1-3, 4, 5, 9, 15, 16, 18, 19   |
| France      | Patients can write/ or add/ delete files, ask for deleting record document, change data. | Authorize/block access to certain information and professionals   | 1, 3-5, 28, 29   |
| Iceland     | No   | Pt. can hide some certain information in the portal,  | 3, 6, 15, 17-19  |
| New Zealand | No   | Certain information is available, i.e. not the whole medical record   | 3-6, 15, 17, 20-23   |
| Norway      | No   | Default access for healthcare professional. Citizens can decide who can access, ask for consent, or blocked.  | 1(NN),2 (MN), 3,6 (GPs on HN), 7, 8 and 9 (WN) 15,18, 19, 27 (Sum. Care Record).   |
| Scotland    | No   | Yes   | 4, 6, 7, 16, 24-27   |
| Sweden      | No   | Patients can block access to certain information; Information release dates (directly or 14 days delay) and whether unsigned notes are shown depends on county regulations. | 1 (single healthcare provider can decide not to release certain parts to patient) 2-4,9,18.<br>6-8, 16 (as separate e-services available for whole population) |

**Functionalities key**

1. Access to entire record
2. Access to summary of record
3. Access to medicine
4. Access to laboratory test results
5. Access to X-ray, MRI, CT, etc
6. Make appointments for GP *Scotland: Request appointments (doesn't specify with whom)*
7. Make appointments at hospital/specialized care *Scotland: Request appointments (doesn't specify with whom)*
8. E-consultations (Patients consult their GP)
9. Access to referrals *Estonia & New Zealand: GP as gatekeepers*
10. Child development *Estonia: Access to child development reports*
11. Access to Medicare Benefits Schedule (MBS)/Pharmaceutical Benefits Scheme (PBS) billing
12. Organ donation wishes *Estonia: Includes consent/refusal for blood transfusion*
13. Apply for official health certificate (eg. for Driver's license)
14. Access to dental records
15. Access to immunization information
16. Renewal of prescription
17. Secure communication between health professionals and patients
18. Access to logs on who has accessed their record
19. Overview of dates for GP visits and hospital admissions
20. Journal (Patient can keep a diary of whatever they want to note)
21. List of diagnoses
22. Goal tracking
23. Calendar
24. Record and monitor blood sugar levels and blood pressure
25. Set and record personal goals for health such as weight and BMI
26. Set and record life goals
27. Access information about particular health conditions
28. Medical certificates / Statements

## 4. Discussion

An increase in citizen's electronic access to their own health data in multiple countries is evidenced by the data presented above. Unsurprisingly these data reveal some variation across when access initiatives were commenced (mostly in the last 3-5 years) and some clustering of similarities in terms of population coverage, registration pro-cesses, patient access controls and editing rights in relation to health data. However, as the column on functionalities highlights there are wide variations on what types of information and care related activities are available to citizens in the different countries studied. These variations can be seen to be intimately related to the history and structure of health care service delivery in each of the individual countries. The data also reveal insights into how different socio-cultural traditions embed concepts on the expected and desired roles for citizens in the management of their own health that raise challenging questions about the transferability of approaches and measurements of success. Positively this comparative analysis highlights that a number of countries are already quite advanced in their provision of citizen access to their own health data, while others are heading rapidly in the same direction. This suggests that further benchmarking and clustering of countries in relation to particular functionalities could be a useful line of enquiry in the future, as long as differences in health care structure, models of service delivery, and socio-cultural traditions pertaining to the patient, are adequately accommodated. Critically future discussions must focus on the anticipated benefits that will be delivered by citizen access and on finding suitable mechanisms and measures to benchmark success over-time.

In this context, this brief multi-country comparison confirms the need for a rapid transition in our research foci away from questions about access, adoption, and use, to more challenging measurement of benefits and impacts. There is a need to generate more detailed insight into whether these electronic systems support the delivery of high-quality low-cost care? Whether these systems are helping to optimize the integration of care enabling more patients to stay out of hospital and/or to live independently for longer in their own homes? And, whether these systems will impact positively on the standardization of clinical best practice to overcome variability in the quality and safety of clinical care? It is anticipated that this paper will stimulate debate on electronic citizen access to health data and the challenges of measuring benefit, and reflection on capacity of different citizens to engage with e-health. Finally, in our conviction in, and excitement about, citizen e-health there is a need to reflect on who the citizens are that will most benefit from the systems implemented [6].

## References

- [1] Hyppönen, H., et al (2015) Nordic eHealth Benchmarking, 15 June 2015 ISBN 9789289341677; 9789289341660 (EPUB) DOI: 10.6027/tn2015-539
- [2] Adler-Milstein, J, Ronchi, E, Cohen, G, Pannella Winn, L & Jha, A (2013). Bench- marking Health IT among OECD countries: better data for better policy. *Jam Med Inform Assoc.* 2013;0:1-6..N.
- [3] Epic Mobile Applications and Portals. <https://www.epic.com/software-phr.php> (Accessed March 2016)
- [4] Cerner Patient Portal. [http://www.cerner.com/solutions/Physician\\_Practice/Patient\\_Portal/](http://www.cerner.com/solutions/Physician_Practice/Patient_Portal/) (Accessed March 2016)
- [5] Microsoft Healthvault. <https://www.healthvault.com/au/en> (Accessed March 2016)
- [6] Showell, C., Turner, P. (2013) "Personal Health Records are Designed for People Like Us", *Studies in Health Technology and Informatics*, **192** (1) pp. 137