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Abstract. While research on the effects of patient access to health records is increasing, a basic understanding of the spread of patient-accessible electronic health records worldwide is lacking. In this survey of healthcare experts with professional and personal experience from 29 countries, we explored the state of patient online record access (ORA). We asked participants whether ORA exists in their country and which information is available through it. Experts in all polled countries reported having some national access to health records, with 6 (21%) countries providing exclusively paper-based records and 23 (79%) countries having ORA. Overview of test/lab results and prescription/medication lists were the most commonly available information. Free-text clinical notes were accessible in less than half of the surveyed countries (12, 41%). We will continue to map the state of patient ORA, focusing on traditionally underrepresented countries.

Keywords. Patient accessible electronic health records, PAEHR, online record access, ORA, patient portal, electronic health record, EHR

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1. Introduction

Patient access to electronic health records (EHRs) has increased worldwide since the turn of the century. In the USA, for example, the Health Insurance Portability and Accountability Act of 1996 gave patients the right to obtain copies of their clinical notes. Still, access to paper notes is cumbersome, time-consuming, and burdensome for patients [1]. In April 2021, following the implementation of the Cures Act, nationwide patient access was rolled out in the USA. In other countries, such as Sweden and Estonia, patients' online record access (ORA) has been available for longer: in the case of Estonia as early as 2008. Much of the current findings point to benefits from reading health records when patient access is available [2, 3]. There has been, however, limited research into the global spread of patient access - whether paper-based or ORA, and what information patients can access [4]. Importantly, little is known about the extent of record access beyond so-called W.E.I.R.D (Western, Educated, Industrialised, Rich, Democratic) countries [5].

The Citizen and Health Data Working Group at the European Federation of Medical Informatics (EFMI) initiated the first steps towards mapping the state of patient-accessible health records worldwide. Our goal was to establish a rudimentary understanding about the state of health record access across the world, namely whether ORA exists, and which information patients can access via ORA.

2. Methods

In order to assess the state of patient ORA on a global scale, we conducted an online survey with experts in EHRs and healthcare. The survey consisted of 15 items, of which 8 were close-ended questions (single- or multiple-choice) and 7 were free-text questions. Items focused on two topics: basic participant information (country of residence, self-rated expertise, area of expertise) and patient access to health records in participant's country (availability of patient access to health records, what health information is available through ORA, ORA to free-text clinical notes). All close-ended questions were mandatory.

The survey was created and distributed through Qualtrics (Qualtrics, Provo, UT). IP addresses and location were not recorded. A survey link was distributed through the professional networks of the research team as well as on social media (Twitter, LinkedIn, and Facebook) between April and September 2022.

There were two parts to the analysis. First, we calculated descriptive statistics related to the participants (expertise rating and area of expertise). Second, we focused on the presence of features in countries (patient access to health records, health records information, and clinical notes). Where there was disagreement between participants on the presence of a feature, the majority response was recorded. Due to the exploratory nature of the study, analysis included descriptive statistics such as count, percentage, median (*M*) and median absolute deviation (*MAD*). Statistics were calculated in JASP v0.16.2 (JASP Team, University of Amsterdam) and the figure was created with Datawrapper. Qualitative analysis of the free-text comments is not reported in this paper.

Data was downloaded to a password-protected drive accessible only to the research team. The survey did not collect sensitive or identifying personal information and was exempt from ethical review in accordance with Swedish legislation. Survey

respondents were informed of the purpose of the survey and that participation was voluntary.

3.   Results

The survey was completed by 156 respondents from 29 countries: Argentina, Australia, Austria, Belgium, Brazil, Bulgaria, Canada, Croatia, Czech Republic, Denmark, Estonia, Finland, France, Germany, Greece, Ireland, Israel, Italy, Netherlands, New Zealand, Norway, Poland, Russia, Spain, Sweden, Switzerland, Turkey, the UK, and USA (see Figure 1). The geographical representation of the sample was uneven, with most responses coming from countries in Northern and Western Europe ($n = 14$, 48%) and North America ($n = 2$, 7%). Almost a quarter of individual responses came from the UK ($n = 34$, 22%), followed by the US ($n = 12$, 8%) and Sweden ($n = 11$, 7%).
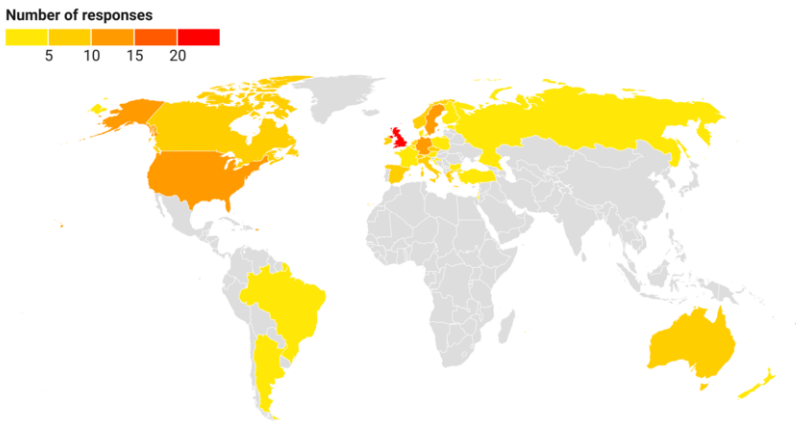

Figure 1. Geographical distribution of responses at the time of analysis.

Participants' self-rated expertise ranged from '0 - No expertise' ($n = 8$, 5.1%), through '1 - Minimal expertise' ($n = 18$, 11.5%) to '5 - Highest expertise' ($n = 23$, 14.7%) with a median rating of $M = 3$ ($MAD = 1$). As seen in Table 1, most reported professional expertise ($n = 103$, 66%) but many also pointed to personal expertise ($n = 82$, 53%).

Table 1. Participants areas of expertise.

	Participants (*Total* = 156)	
	n	**%**
Area of expertise [a]		
Professional expertise		
Research	50	24.4%
Healthcare professional	21	10.0%
Service development & management (non-IT)	14	6.5%
Service development & management (IT)	12	6.0%
Policymaking & government	6	2.5%
Personal expertise		
Patient experience	70	34.3%
Caregiver experience	8	5.1%
Activism	4	2.0%
Undetermined	11	5.5%

[a] Multiple-choice question, the total does not add up to the sample size.

Based on expert responses, all 29 countries provide patients with some form of access to their health records, be it paper-based or ORA (Table 2). Six countries (20.7%) were reported to exclusively provide paper-based access through the public health system (these were the Czech Republic, Germany, Greece, Ireland, Russia, Switzerland). The remaining 23 countries (79%) had patient ORA, with or without the need for a formal request. Of the countries that have ORA, participants indicated that patient portals were available nationwide in 13 (44.8%) countries, regionally in 4 (13.8%) countries, and limited to certain medical providers in 5 countries (17%).

Table 2. Number of countries with patient access to online health records.

	Countries (*Total* = 29)	
	n	**%**
Access to health records [a]		
Paper-based copy after formal request	18	62.0%
Access through online patient portal after formal request	3	10.3%
Access through online patient portal without a formal request	15	51.7%
No access	–	–
Information available to patients in online health records [a]		
Lab / Test results	22	75.9%
Prescriptions / Medication list	20	69.0%
Immunisations	15	51.7%
Diagnoses and conditions	15	51.7%
Discharge notes / Summaries / Epicrises	14	20.3%
Referrals	9	31.0%
Health information about dependants	8	27.6%
Diagnostic imaging	4	13.8%
Access to free-text clinical notes from … [a]		
Primary care	8	27.6%
Hospital/Secondary Care (non-psychiatric)	7	24.1%
Hospital/Secondary Care (psychiatric/psychotherapy)	3	10.3%
Social Work/Municipality Care/Home Care	2	7.0%
No patient access to free-text clinical notes	1	3.5%

[a] Multiple-choice question, the total does not add up to the sample size.

The type of information most commonly reported as being available to patients through ORA, was lab/test results (*n* = 22, 75.9%) followed by prescriptions/ medication list (*n* = 20, 69%), while diagnostic imaging was the least (*n* = 4, 13.8%). Free-text clinical notes were also not commonly made available to patients, with less than half of the countries (*n* = 12, 41%) providing them at some level of care (Table 2).

4. Discussion

Access to health records exclusively through paper-based copies in this exploratory international survey was less extensive as ORA. Even among countries offering ORA, there was wide variation with respect to what patients could access. The most commonly reported information available via ORA was lab/test results, prescriptions/medication lists, immunisations, and diagnoses. Notably, even among countries offering ORA, access to online free text entries was less extensive.

This study has several limitations. First, while we strived to survey experts, many participants did not consider themselves to be such despite working professionally with EHRs or having extensive patient experience. This brings the possibility that potential respondents did not complete the survey due to a perceived lack of expertise. Relatedly,

there was a limited number of replies from some countries, particularly those in Southern Europe and South America, which resulted in an equal number of conflicting answers and prevented the record of a majority response. It is crucial to increase the number of responses per country to overcome limitations stemming from individual knowledge such as lack of experience with features, e.g. access to dependant's records or regional differences. Further efforts will be made to encourage participation. Last but not least, W.E.I.R.D. countries were overrepresented in this preliminary dataset [5]. In order to gain a truly global perspective on patient record access, we must broaden the geographical representation. This will be the focus of our future work.

We will continue data collection through targeted survey distribution with the aim to create an open collaborative database of global patient ORA. We foresee it to include basic details about a given country's national health records platform, relevant laws on patient access to health records, and a functions list.

5.   Conclusions

The findings from this survey give a first look at the global advance of ORA but its accurate mapping will not be possible without experts from underrepresented countries. The EFMI Citizen and Health Data Working Group invites experts with professional and personal experiences to join us in researching patient ORA.

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