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Citizens' Access to Online Health Information – An International Survey of IMIA Member Countries

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Abstract. Citizens' access to their online health information is pivotal. Therefore, this study examines citizens' access to their online health information across countries and healthcare settings. The study is based on a survey design targeting the 98 IMIA representatives of the national societies. Results indicate that *Test results* and *Medications* are the two types of online information that citizens in most cases have access to. Ten countries provide citizens access to all the different types of information included in the study. That relatively few countries provide citizens access to all the included types of online health information underscores the importance of continuous emphasis on accessibility and research within this field.

Keywords. Citizens, accessibility, health information, imia, survey

1. Introduction

Citizens' access to their personal health information and data online is focal in today's digitalized healthcare systems for various reasons. First, from a democratic perspective, every citizen has a right to have access to their data. Second, digital healthcare systems need to be accessible and based on a foundation that promotes equity in healthcare. That is, digital healthcare systems should not exacerbate inequities in healthcare but instead act as innovations that bolster equity in access [1,2]. Third, consumer managed care, emphasizes 'the active patient' or one who is involved in their own care, health decisions, and treatment, and this concept is promoted in current health policies. However, if citizens are to self-manage their health and chronic conditions, access to their personal online health data is required. Access to personal health information or health data is an important first step for citizens to start leveraging their health data to manage their health and chronic conditions [3]. Thus, given the importance of

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accessibility in digital and citizen-centered healthcare systems, this study examines the extent to which citizens are able to access their personal health data online in the IMIA member countries.

2. Methods

In this study, we administered a questionnaire to 98 International Medical Informatics Association (IMIA) representatives. The questionnaire was distributed via email in January 2021 with a deadline for responding within four weeks. IMIA representatives from 29 different countries completed the questionnaire resulting in a response rate of 28%.

The questionnaire consisted of thirteen questions requiring approximately 4 minutes to complete. The scope of this paper is limited to seven questions about citizens' access to their online health data (e.g., medical history, diagnoses, medications, treatment plans) in public/private as well as hospital/ambulatory settings:

- Which country do you represent?
- What type(s) of information do citizens in your country have online access to from **all hospitals** in a public health care system?
- What type(s) of information do citizens in your country have online access to from **some hospitals** in a public health care system?
- What type(s) of information do citizens in your country have online access to from **all ambulatory care settings** in a public health care system?
- What type(s) of information do citizens in your country have online access to from **some ambulatory care settings** in a public health care system?
- What type(s) of information do citizens in your country have online access to from **private hospitals** or Health Maintenance Organizations (HMOs) hospitals?
- What type(s) of information do citizens in your country have online access to from **private ambulatory care settings**?

Data were analyzed by the use of SPSS and MS Excel. Descriptive statistics and cross-tabulations were used to provide overviews of associations between countries, healthcare settings and information types.

3. Results

The results section consists of two subsections, one analyzing the types of information citizens can access in different healthcare settings and another comparing citizens' access to online health data across countries.

3.1. Citizens' Access to Information in Public, Private and Ambulatory settings

The analysis revealed that *Test results* are the most accessible type of information in the countries that responded. *Test results* were on average accessible in 11.8 countries across healthcare settings (Figure 1); accessible in *some hospitals and Private hospitals/HMOs* in 15 and 14 respectively and in *some ambulatory care settings* and *private ambulatory care* in 13 and 12 countries respectively (Table 1).

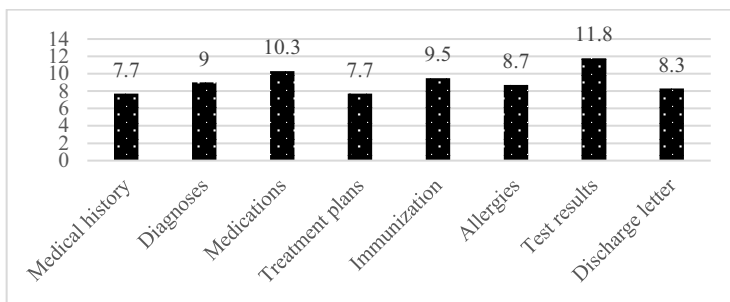


Figure 1. Types of online health data that citizens can access on average across healthcare settings (n=29).

Table 1. Types of online health data that citizens can access across healthcare settings (n=29).

	All hospitals	Some hospitals	All ambulatory settings	Some ambulatory care settings	Private hospitals/HMOs	Private ambulatory care settings
Medical History	6	9	6	10	7	8
Diagnoses	7	11	6	12	9	9
Medications	10	13	9	13	9	8
Treatment plans	6	9	6	9	7	9
Immunization	8	10		12	8	
Allergies	8	11	7	12	7	7
Test results	9	15	8	13	14	12
Discharge letter	6	12			7	

Medications is the information type that on average has the second highest accessibility; 10,3 countries across healthcare settings (Figure 1). Medications are most frequently accessible in some hospitals (13) and some ambulatory care settings (13) (Table 1).

The six remaining information types are on average accessible in 7,7 (Medical history, Treatment plans), 8,3 (Discharge letter), 8,7 (Allergies), 9 (Diagnoses) and 9,5 (immunization) countries (Figure 1).

When analyzing general patterns concerning the association between healthcare settings and accessibility to information across the different types of information, numbers show that information is most frequently accessible through *some hospitals* and *some ambulatory care settings* respectively accessible in 11,3 and 11,6 countries on average.

In the four remaining healthcare settings information, across information types, is accessible in respectively 7 (All ambulatories), 7,5 (All hospitals), 8,3 (Private ambulatory care settings) and 8,5 (Private hospitals/HMOs) countries.

3.2. Information access – comparison across countries

As table Table 2 shows, the maximum number of information, which in this study concerns six information types in ambulatory settings and eight types of information in hospital settings, are accessible in respectively 13 and 10 countries.

Table 2. Number of information types that citizens have online access to across healthcare settings (n=29)

	Some hospitals	Some ambulatory care settings	Private hospitals/HMOs	Private ambulatory care settings	Number of countries
Access to at least 1-3 types of information	5	3	7	5	20
Access to at least 4 types of information	1	3	2	2	8
Access to at least 6-7 types of information	3	8	2	5	18
Access to 8 types of information	6		4		10

So, who are these frontrunners? Ten countries are particularly good at providing their citizens with access to online health data. Access to the maximum types of information in some hospitals (8) is possible in The Netherlands, Finland, Denmark, Sweden, USA and Canada. Access to maximum types of information in Private hospitals/HMOs (8) is possible in Finland, USA, Taiwan and South Africa.

Access to the maximum amount of information in some ambulatory care settings (6) is possible in The Netherlands, Finland, Denmark, Sweden, United Kingdom, USA, Canada and New Zealand. Access to the maximum amount of information in private ambulatory care settings (6) is possible in Finland, USA, New Zealand, Taiwan and South Africa.

Finland and USA are the only countries that have the maximum amount of information accessible across the public/private sector and hospital/ambulatory settings. In The Netherlands, United Kingdom, Denmark, Sweden and Canada, online health information is particularly accessible through public services while these information types are primarily accessible through private providers in Taiwan and South Africa.

4. Discussion

Based on the results of this study accessibility to online health information varies across, countries, healthcare systems, and healthcare settings and is additionally determined by the type of information required. Only in ten countries, citizens are able to access the maximum amount, 6 to 8 different types, of health information included in this study. Among these frontrunners, three are Nordic countries (Sweden, Finland and Denmark), two are North American countries (USA and Canada), two are European (Netherlands and United Kingdom), one is African (South Africa), one is

Asian (Taiwan) and one is from the continent of Oceanian (New Zealand). Hence, a variety of continents are represented; nonetheless, North America and Europe are dominating the picture whereas a continent like South America is underrepresented.

5. Conclusions

This study provides a country-specific perspective on accessibility to online health information but differences in access to health information might also be explained by regional variations characterized by the organization of health systems and cultural differences [4]. Individual factors such as health literacy and digital literacy, are another group of variables which are required to achieve a patient-centred health system where the citizens are able to take care of their health [5].

Challenges that need to be addressed considering the principles in The IMIA Code of Ethics for Health Information Professionals [2]. Thus, the principle of autonomy, emphasises that all persons have a fundamental right to self-determination, whereas the principle of equality and justice, underscores how all persons are equal as persons and have a right to be treated accordingly [2]. In other words, a continuous focus in the IMIA member countries to ensure a high level of accessibility to online health data is encouraged.

References

- [1] The World Health Organization, Office of the United Nations High Commissioner for Human Rights. The Right to Health, (2008). <https://www.ohchr.org/en/publications/fact-sheets/fact-sheet-no-31-right-health>.
- [2] The IMIA Code of Ethics for Health Information Professionals, (2016). <https://imia-medinfo.org/wp/imia-code-of-ethics/>.
- [3] Eriksen JE, Byholm A, Bertelsen P. The association between patient-reported outcomes (PROs) and patient participation in chronic care: A scoping review. *Patient Educ Couns*. 2022 Jan;105(7):1852-12, doi: [10.1016/j.pec.2022.01.008](https://doi.org/10.1016/j.pec.2022.01.008).
- [4] Hägglund M, Scandurra I. User Evaluation of the Swedish Patient Accessible Electronic Health Record: System Usability Scale. *JMIR Hum Factors*. 2021 Jul;8(3):10, doi: [10.2196/24927](https://doi.org/10.2196/24927).
- [5] Eriksen JE. Purpose, Functionality and Reconceptualization of Patient-Reported Outcomes – A Patient Participation Perspective on PRO in Clinical Practice Post its Digitalisation, 1st ed. Aalborg University Press, Aalborg, 2021.