Do patients want to know who accesses their Personal Health Information?

A questionnaire to university students

Sandra Reis[1,2] , Ana Ferreira[1,3] , Pedro Vieira-Marques[1,3] ,Cátia Santos-Pereira [2,4,5], Ricardo Cruz-Correia[1,2,3]

[1] Faculdade de Medicina da Universidade do Porto – FMUP

[2] HealthySystems - HLTSYS, Lda

[3] Center for Research in Health Technologies and Information Systems – CINTESIS

[4] Instituto de Engenharia de Sistemas e Computadores, Tecnologia e Ciência - INESC TEC

[5] Faculdade de Engenharia da Universidade do Porto – FEUP

Porto, Portugal

sandra.reis@hltsys.pt; amlaf@med.up.pt; pmarques@med.up.pt; catiapereira@hltsys.pt; rcorreia@med.up.pt;

Abstract — **Personal Health Information (PHI) is collected and used by multiple health professionals and multiple information systems, and usually the patient does not know who accesses their information, when and for what purposes. According to USA (HIPAA) and EU legislation (GDPR) a patient has the right to see his/her clinical information and to know who has access to it, however, the process of obtaining all this related information is still time consuming and complicated. We aim to investigate the opinion of university students regarding the existence of a tool to verify whose healthcare providers access their health information. A web-based questionnaire was designed, 33404 university students were contacted and 589 answered it (1.8% response rate). 90.7% of participants recognize that a tool with those characteristics is important, and 71.5% of them agree to use that tool. In general, we can consider that although the vast majority of participants did not show great knowledge about available healthcare legislation (81%) and that about half of respondents do not know about the use of their data by other parties (52%), more than 90% consider important the existence of a tool to view who accesses their health information. We intend to continue research on this topic and design an access control tool that can empower patients to better control their privacy and rights so to address the gaps existing in the area.**

Keywords - Personal health information, access control, patient access to records, patient empowerment, GDPR, HIPAA.

I. INTRODUCTION

Every day Personal Health Information (PHI) is collected and used by multiple users like physicians, researchers, pharmaceutical industry, statisticians, etc. [1], who recognize that sharing PHI increases quality of health care and reduces medical costs and errors [2]. However, there is no consensus about how and what PHI should be disclosed to the patient. A patient may prefer that his/her PHI remain private but from a healthcare professional's perspective the disclosure of this information may assist with a diagnosis, and help to understand and prevent diseases [1,2]. Health care should promote the acceptance of patient's needs, and therefore allow the patient to access his/her clinical information as well as promote the power to choose. According to HIPAA (Health Insurance Portability and Accountability), the legislation in the United States that safeguards the safety and privacy of clinical information, a health system must allow a patient to access his/her clinical information and to know who has access to his/her PHI [3]. In Europe, with the new GDPR (General Data Protection Regulation) in force in May 2018, the right of patients to access their clinical information [4] and to know who accessed it, becomes even more evident and required [5]. According to legislation a patient has the right to see his/her clinical information and to know who has access to it however, the process of obtaining all this related information is still time consuming and complicated, requiring formal authorizations from health institutions [5,6]. Following these requirements, healthcare Institutions need to create secure and usable means to fulfill this legislation as well as patients' requirements [7]. Knowing what health professionals have accessed the clinical data of patients may be challenging, even when institutions' systems keep the access logs of health professionals. Often these access logs are kept in each system and not in one single system, making it difficult for institutions to integrate and show this information [8]. In Portugal, there is a public tool created by the National Health Service that allows the patient to view which health professionals' accessed their national patient clinical summary (named PDS - Plataforma de Dados de Saúde - Health Data Platform). However, this tool only provides access history for that national platform, and not the accesses performed in the different databases of hospitals or primary care patient records [9].

Following the identification of this gap, this study aims to investigate the opinion of a determined population (e.g., university students) regarding a tool to verify whose healthcare

providers have had access to student's health information. We expect to understanding people's awareness about this issue and which requirements a tool should have to fulfill the identified needs. The university student population can be relevant as they are expected to be proficient in technologies, and more aware of their rights when compared to the overall population. They are also expected to shape social opinion for the next decades.

II. METHODOLOGY

A. Study Design and Data Collection

A web-based questionnaire was designed to examine the population's interest in having access to a tool that allows patients to know which healthcare providers access their health information in the institution's information systems. For the questions' development, it was taken into account the fact that the addressed population might not have knowledge about data protection or about how health information flows in health institutions. For this reason, the applied questions were simple, easy to understand and without concepts that needed previous knowledge. To evaluate the clarity of the information, as well as collect critiques and suggestions for the improvement of the questionnaire, a pre-test questionnaire was carried out. This test comprised 38 people and was available from the 9th of November 2017 until the 13th of December 2017. From this pre-test new questions emerged, which we considered pertinent to also integrate in the questionnaire, and corrected some existing ambiguities. After alterations, the final questionnaire was shared by email and applied online between the 2nd and the 12th of January 2018.

B. Study Participants

The sample we chose was a convenience sample, from the student's community at University of Porto. The questionnaire was sent to the target population via the institutional email, with a total of 33404 emails.

C. Questionnaire

The language of the questionnaire was Portuguese and included 29 questions divided into 6 parts: a) personal information (5 questions); b) questions to understand if the person was accustomed to the use of technologies (3 questions); c) questions to understand the level of knowledge and concern about health data and the frequency with which they use hospital institutions (10 questions – 6 of them using the Likert Scale); d) data protection questions, namely knowledge on the new GDPR (3 questions); e) a question about the importance of a tool that shows to patients all the health professionals that see and/or change their health information in different hospital systems (1 question - if this answer was negative the questionnaire ended here; and 2 more questions about the tools benefits); and f) questions about characteristics that may add interest to the tool (5 questions).

D. Data Analysis

To perform data analysis, we used SPSS® in which statistical description measures were applied in order to evaluate the answers. Because most data were categorical variables, the results are shown as numbers and frequencies. To compare the results in different groups medians and quartiles were calculated.

Also a Pearson's chi-square test was performed and a $p < 0.05$ was considered for a statistically significant value.

III. RESULTS

589 participants answered the questionnaire (1.8% response rate), with all answered questionnaires being completed and usable. The submissions were recorded online, on the questionnaire form, and exported to a spreadsheet for analysis. Results from the questionnaire are shown on table I and II, the rows may not add to 100% due to rounding.

A. Personal and Technological Information

Information of 589 participants, 71% female and 29% male was analysed. The majority of answers were from participants aged between 18 and 30 and regarding academic qualifications, the most common was the Bachelor's degree, and most of the participants are not on a health related course nor are health professionals. Participants who are caregivers of children, elderly or both were 8%. Most participants have a daily contact with technologies, 76% use a mobile phone daily to see their email and 84% use their computer to work/study. When asked about changing passwords 36% of participants recognized that they never or rarely changed theirs.

Personal and Technology information results are presented in table I.

B. Health Information Access Knowledge

The results of the questionnaire reported that a majority of participants, 56%, went to a health institution 2 to 6 times in the last year, all the results can be seen in table I.

Regarding the statements evaluated with a Likert Scale, 39% of participants agree in part with the statement "I know which of my data health institutions have"; 27% agree in part with the statement "I know which health professionals have access to my health information"; also in the statement "I am concerned that a health professional, with whom I have never had contact, can see my health information", 24% of participants agree in part. About the statement "I am concerned that my health data is viewed and studied by students (medicine/ nursing/ diagnostic technicians etc.)", 23% disagree in part; 24% disagreed in part with the statement "I am concerned that my health data will be used for studies in the pharmaceutical industry" and 48% of participants strongly agree with "I consider the protection of my health data important". All results are available in table II.

Regarding the Portuguese National Health Service user portal, 63% of participants never used it and of those who used it, only 24% were aware of the access history tool. However, 90% of participants consider this functionality useful, full results are presented in table I.

C. Legislation Knowledge

Only 19% had heard about the new GDPR and only 16% had the knowledge that the GDPR indicates that patients have the right of accessing all their health information. When asked whether they ever give informed consent to a health institution, 61% of participants never did. Results concerning legislation knowledge are available in table I.

TABLE I.   QUESTIONNAIRE ANSWERS (1)

Age Group				
	<18	[18,30[	[30,40[	[40,60[	[60,70[
n (%)	6 (1%)	503 (85%)	50 (9%)	27 (5%)	2 (0.3%)
Academic Qualifications				
	3rd cycle	Secondary education	Bachelor's	Master	PhD
n (%)	2 (0.3%)	187 (32%)	249 (42%)	137 (23%)	14 (2%)
Profession				
	Health Student	Health Professional	Non Health		
n (%)	176 (30%)	46 (8%)	367 (62%)		
Caregiver				
	Non Caregiver	Children caregiver	Elderlies caregiver	Children & elderlies	
n (%)	545 (93%)	24 (4%)	7 (1%)	13 (2%)	
Email on Smartphone				
	Daily	1/ 2 week	1/ 2 month	1/ 2 year	Never
n (%)	449 (84%)	92 (16%)	29 (5%)	6 (1%)	5 (1%)
Laptop at work				
	Daily	1/ 2 week	1/ 2 month	1/ 2 year	Never
n (%)	493 (84%)	69 (12%)	16 (3%)	6 (1%)	5 (1%)
Password change				
	Once a month	Once a year	When other know	Never/Rarely	NA
n (%)	18 (3%)	106 (18%)	332 (56%)	67 (11%)	49 (8%)
Visits in the last year				
	0	1	[2,6[	[6,12[	>12
n (%)	35 (6%)	106 (18%)	332 (56%)	67 (11%)	49 (8%)
Knowledge of the Plataforma de Dados de Saúde				
	Yes	No	Don't know/ Don't want to answer		
n (%)	200 (34%)	371 (63%)	18 (3%)		
Knowledge of Access History on the Plataforma de Dados de Saúde				
	Yes	No	Don't know/ Don't want to answer		
n (%)	66 (11%)	520 (88%)	3 (0.5%)		
Importance of Access History				
	Yes	No	Don't know/ Don't want to answer		
n (%)	530 (90%)	24 (4%)	35 (6%)		
Knowledge of GDPR				
	Yes	No	Don't know/ Don't want to answer		
n (%)	110 (19%)	476 (81%)	3 (0.5%)		
Patients data on GDPR				
	Yes	No	Don't know/ Don't want to answer		
n (%)	92 (16%)	490 (83%)	7 (1%)		
Informed Consent				
	Yes	No	Don't know/ Don't want to answer		
n (%)	137 (23%)	360 (61%)	92 (16%)		
Tool Importance				
	Yes	No	Don't know/ Don't want to answer		
n (%)	534 (91%)	28 (5%)	27 (4%)		
Tool can give more control over health information				
	Yes	Maybe	No	Don't know	
n (%)	351 (63%)	192 (34%)	10 (2%)	8 (1%)	
Alarms to notify accesses				
	Yes	No	Don't know/ Don't want to answer		
n (%)	391 (70%)	116 (21%)	53 (10%)		
Tool's Frequent Use				
	Annualy	Semi-annualy	Monthly	Weekly	NA
n (%)	48 (9%)	127 (23%)	221 (40%)	112 (20%)	53 (9%)

TABLE II.   QUESTIONNAIRE ANSWERS (2)

	SA	AP	NAD	DP	SD
I know which of my information health institutions have	13%	39%	15%	22%	11%
I know which health professionals have access to my health information	26%	27%	8%	19%	19%
I am concerned that a health professional, with whom I have never had contact, can see my health information	20%	24%	18%	19%	18%
I am concerned that my health data is viewed and studied by students	12%	20%	19%	23%	26%
I am concerned that my health data will be used for studies in the pharmaceutical industry	19%	20%	15%	25%	21%
I consider the protection of my health data important	48%	28%	17%	5%	3%

SA- strongly agree; AP – agree in part; NAD – not agree or disagree; DP – disagree in part; SD – strongly disagree

D. Tool

When questioned about the importance of a tool that shows to patients all the health professionals that see and change their health information in different hospital systems, 91% of participants consider it important and 5% do not consider a tool with these characteristics important, and therefore finished the questionnaire in question 17. The remaining of the questionnaire was answered by 561 participants. About the benefit of the tool, 63% of participants consider that it can give the user a greater control over their health data. When asked to the participants who had someone in their care if the tool could be useful for greater control of the person they care, 83% think so.

E. Tool Characteristics

Concerning the tool characteristics, the first question was to select the two preferred modes to view the information, the answer chosen by most participants was the web page option (473 selections), as shown in figure 1.

When asked about what information they would like to access on the tool (by selecting the four most preferred answers), the most preferred answer was "name and health professional's profile" (505 selections), followed by "history of patient's events (doctor's appointments, medical exams, surgeries etc.)" (435 selections), then "reason for access" (406 selections). All results can be seen in figure 2.

As to alerts, most participants (69.7%) would like the tool to notify them when someone accesses their health information. Results for this answer are presented in table I.

When faced with the question if they would use a tool with the characteristics previously mentioned 71.5% confirm that they would, 26.6% are not sure and only 1.2% would not use it.

Considering that in a total of 589 participants, 401 confirmed they would use the tool, we can assume with a confidence level of 95% that if a tool with these functionalities was made available, between 64.1% and 72.1% of the representative population of our sample would use it. Those
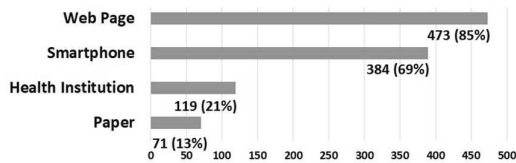
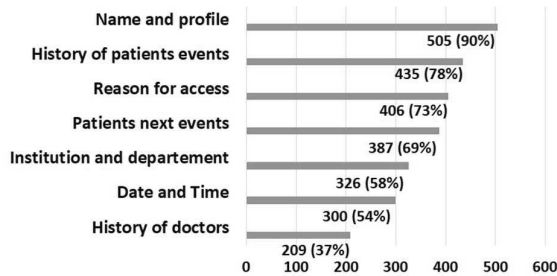Figure 1. Modes to view the tool. Multiple choice allowed.

Figure 2. Information to view on the tool. Multiple choice allowed.

who answered that they would use the tool, 43.9% would use it monthly, 24.9% weekly, 21.9% semi-annually and 5.2% annually, as presented in table I.

About the 5% of participants who do not consider the tool important, reviewing the answers of their questionnaire we found interesting answers. In the statement "I am concerned that a health professional, with whom I have never had contact with, can see my health information", 71% of them strongly disagree or disagree in part with the statement, the same results have been revealed in the other two statements about health students seeing their health information and about their health data being used in pharmaceutical studies. Also, 50% of these participants did not believe in the importance of the history accesses tool of the national health portal. Even though 57% of these participants strongly agree or agree in part that they give importance to the protection of their health data, they stated that it is no problem for them to have their health information accessed whenever and by whoever wants to, so they are not interested in having a tool that shows them those records.

F. Analysing Groups

In order to understand if the groups of people we came across, had different knowledge and different perspectives in this issue we calculated the medians of the answers to some questions and compared them in the different groups. The selected questions were the statements to agree or disagree on and the question about the importance of the tool. We present the results in table III, they are shown as median values [first quartile value; third quartile value]. The statements and questions analysed were: "I know which of my information health institutions have", "I know which health professionals have access to my health information", "I am concerned that a health professional, with whom I have never had contact, can see my health information", "I am concerned that my health data is viewed and studied by students (medicine/ nursing/ diagnostic

technicians etc.)", "I am concerned that my health data will be used for studies in the pharmaceutical industry", "I consider the protection of my health data important" and "Do you consider important the existence of a platform for patients to know all the health professionals who see and/or change their health information in different hospital systems?". Also, the answers were transform in ordinal numbers to calculate the median, for the 6 statements the correspondent answer is: 1- Strongly agree; 2 - Agree in part; 3 - Does not agree or disagree; 4- Disagree in part; 5 - Strongly disagree. To the question "Do you consider important the existence of a platform for patients to know all the health professionals who see and/or change their health information in different hospital systems" the answer correspondent is: 1- Yes; 2 – Do not know or do not want to answer; 3 – No.

Comparing the health group with the non-health group, these groups were created considering the answers from the question "Are you a health professional, a student in health area, or neither?" given in the questionnaire, most of the medians between the groups were not significant. However, the median of the answers to "I know which of my information health institutions have" and "I know which health professionals have access to my health information" were shown to be significant. The health group agrees more with those statements than the non-health group, so participants in the health area seem to be better informed about what information is kept by the healthcare institutions and what types of health information do health professionals have access to. Regarding the remaining questions, no statistically significant differences were found between the medians in both groups, as described in table III.

Another defined group was based on the data obtained from the question about whether participants had ever heard of GDPR. Participants with positive responses were allocated to one group, and those with negative responses to another. For the purpose of this analysis participants who did not know or did not want to answer were not taken into account. When the medians were analysed considering these defined groups, two of the questions were significantly different. One of those is the statement concerning health information being used for pharmaceutical industry studies. The median of those who know about GDPR reflects higher concern than those who do not know about the legislation. Also, the statement that emphasizes the concern of participants in the protection of their health data, presented a median that shows more concern in participants who are aware of the legislation, as presented in table III.

The next two comparison groups were based on the participants' habit of changing passwords, for these groups the answers to the question "Do you usually change the passwords of your email and/or facebook?" were used. One group comprises respondents with the habit of changing passwords "at least once a month" and "at least once a year". The other group is composed of participants who answered they change passwords "only when others have access to the password" and "never or rarely". Participants who did not know or did not want to answer were not taken into account.

	Health (n=222)	Non-health (n=367)	P value	GDPR (n=110)	Non-GDPR (n=476)	P value	Passwords (n=179)	Non-passwords (n=380)	P value
I know which of my information health institutions have.	2 [2;4]	3 [2;4]	**0.000**	2 [2;4]	2 [2;4]	0.731	2 [2;4]	3 [2;4]	0.103
I know which health professionals have access to my health information.	2 [1;4]	3 [2;4]	**0.002**	2 [1;4]	2 [1;4]	0.609	2 [1;4]	2 [1;4]	0.144
I am concerned that a health professional, with whom I have never had contact, can see my health information.	3 [2;4]	3 [2;4]	0.658	3 [2;4]	3 [2;4]	0.359	2 [2;4]	3 [2;4]	**0.046**
I am concerned that my health data is viewed and studied by students.	4 [2;5]	3 [2;4]	0.200	3 [2;4]	4 [2;5]	0.602	3 [2;4]	4 [2;5]	**0.025**
I am concerned that my health data will be used for studies in the pharmaceutical industry.	4 [2;4]	3 [2;4]	0.391	2 [1;4]	3 [2;4]	**0.044**	3 [2;4]	3 [2;4]	0.115
I consider the protection of my health data important.	1 [1;2]	2 [1;3]	0.229	1 [1;2]	2 [1;3]	**0.001**	1 [1;2]	2 [1;3]	**0.005**
Tools Importance.	1 [1;1]	1 [1;1]	0.069	1 [1;1]	1 [1;1]	0.054	1 [1;1]	1 [1;1]	0.084

Median [Q1;Q3]

Considering the results available in table III, the group that changes passwords regularly shows greater concern in having health professionals with whom they have never had contact with to see their health information. Also in the statement "I am concerned that my health data is viewed and studied by students" the median is significantly different in the analysed groups. The participants of the group that do not change passwords regularly are not as concerned about their health data being seen by health students as the group that changes passwords regularly. Also, the statement about the concern of participants in the protection of their health data, presented a median that shows more concern in participants who change regularly their passwords, as presented in table III.

IV. DISCUSSION

In general, we can consider that although the vast majority of participants did not show great knowledge about the legislation (81%), about half do not know about the use of their data (52%) nor which professionals access that data (53%), more than 90% consider important the existence of a tool to view who accessed their health information.

A. Legislation awareness

Even when the new regulation comes into force in May 2018 the lack of knowledge regarding that legislation is evident, possibly justified by the lack of information from mass and social media. This can also justify the lack of interest that some people have in protecting their health data. Nevertheless, questionnaire results show that although participants have little knowledge on privacy and data protection (19%) they realize the importance of a tool to search who accesses and uses their health data.

A study by Tierney et al. to health professionals revealed that 46% of participants strongly agreed or agreed in part that the information present in an EHR is owned by the patient, this indicates that the rest are not aware of the legislation [10]. Comparing with our study these results are higher, however this difference in results can be justified by the difference in population and also the fact that the question is considerably different. Nevertheless, in both studies is recognizable that legislation is not yet widely known by ordinary citizens.

Being more informed and more concerned about the use of their data, those who know GDPR, consider the pharmaceutical studies possibly something secondary to their health care and therefore are more concerned with the use of their data for this specific purpose.

B. Health Information Access Awareness

Health professionals and non-health participants are more concerned (46% e 33% respectively) when compared to health students (26%), about students in health areas viewing their health information. This is an expected result since students are in fact those who use and need the data to study.

Considering the 93% of health professionals who believe that an access control tool would be important for the patient, we can say there was a great adherence on the part of health professionals in our study. Slightly different from Tierney et al. study in which 54% of health professionals strongly agree or agree in part that it is ok for patients to have control of who saw their EHR (electronic health record) but only 42% strongly agree or agree in part on this being a good thing for patients [10]. Since the Tierney study was conducted a few years ago (3 years), this difference in results can be justified by the increase in the disclosure of data protection information. Another justification may be the difference in population. The need to keep the patient to rely and trust on health professionals and their work, more than ever, may be a factor for the health professional to accept this transparency of information. The fact that health group participants are more familiar with health systems that keep patient's information and all the dynamic of health institutions, can justify the greater knowledge that they consider to have about what they are and who sees their health information.

Those who change passwords regularly show more concern about data security and privacy and they do not want "strangers" to see their most personal information. For this reason, they are more worried that health students and health professionals, who they have never had contact with, to see their health information.

C. Tool Characteristics

From the questions about the characteristics of the tool it was found that the preferred way to use the tool was through a web page. Considering the frequency that the user would use the tool, it makes sense that that is an easier way to access data without being intrusive into the user's life. Also considering that our sample had a very technological background it was expected that this option would be preferable to them. The questionnaire also allows us to realize that the most important information in the tool for a user would be the name and profile of the healthcare professional who accessed the information, followed by the patient's own events (like doctor appointments, exams, etc.) and the reason for seeing the information. When these three pieces of information are combined the user can more easily understand whether the access to his/her information was made in the context of a health episode or not. Therefore, this is a mandatory requirement for the development of a new tool in order to promote patient's empowerment.

D. Limitations

One limitation of this study is the number of responses to the questionnaire which manifested a very low response rate (1.8%), only 589 out of 33404. This value can be justified by the fact that the questionnaire was sent through an institutional email that is often recipient of questionnaires for the same purpose, which leads to students' disinterest to answer and also the existence of emails that are not used by the students. Our population was students of higher education in a metropolitan area, and although this can be one of the target audiences for the tool, we would need to test with the general public. This will be approached in future work. Because our sample is very homogeneous and has mostly the same personal characteristics, like age, academic qualifications and technological habits, it is not possible to aggregate and compare responses of participants with those attributes. In addition, although the results are positive regarding the participants' intention to use the tool, more research is needed to confirm this assertion.

V. CONCLUSIONS

GDPR forces that healthcare institutions must maintain records of all processing activities and be able to easily report on personal data use and processing compliance. The implementation of software tools that provide detailed audit logs including changes and usage are essential to automate this process and guarantee logs integrity.

The results of this study show that participants would have a great interest in having access to such tool giving us the motivation to continue with this research and in the future to give patients the opportunity to have access and beneficiate from it. With the results of the questionnaire, we intend to develop that tool. The development of this tool will be done side by side with stakeholders, and will take into account a very strong component of security and privacy that is clearly necessary given the personal and sensitive information that it comprises. We also intend to focus on the usability of the tool so that it is easily used by anyone regardless of their age, technical expertise or knowledge of existing legal requirements.

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