Accessing and Sharing Electronic Personal Health Data

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Abstract: An increasing attention has been given to personal health data (PHD) research over the last years. The rise of researchers' interest could be attributed to the increasing amount of PHD that are stored across various databases, as a result of individuals' rapidly-evolving digital life. Accessing and sharing PHD is essential to create personalized health services and to involve patients in the design process of these services. This paper conducts a survey of literature to present an overview of literature about accessing and sharing of PHD. This study aims to identify limitations in research and propose future directions. Sixteen studies were selected from various bibliographic databases and were classified according to three criteria: research type, empirical type and contribution type. The results provide a preliminary review with respect to access and sharing of PHD, addressing a need for more research about PHD accessibility and for solution proposals for both topics.

1 INTRODUCTION

The development of information and communication technologies (ICT) and their adoption in everyday life, has resulted in a growing amount of personal data that are stored across different digital platforms (Karampela et al., 2018a; Carroll and Richardson, 2017). ICT has changed the way the organizations and companies handle data and have been seen to hold the potential to increase the value and quality in provision of healthcare services (Raghupathi and Raghupathi, 2014). Healthcare industry undergoes a transformation moving towards models that aim to exploit electronic medical records EMRs and personal health records PHRs to create more personalized interventions for patients (Lee et al., 2017).

Electronic Health Records EHRs are records for patients' medical data such as medication and medical history or laboratory tests. EHRs are administrated by healthcare professionals and organizations (Ouhbi et al., 2017). In contrast to EHRs, PHRs are records that consist of health and wellness data related to the care of users and managed by them across their life span. The adoption of PHRs has various potential benefits. In fact, PHRs allow users/patients to access their health information and have been seen to promote self-management of diseases (Tang et al., 2006). Besides EHRs and PHRs, mobile PHRs (mPHRs) solutions have also emerged to facilitate the management of health information, especially useful in cases of patients with chronic conditions. mPHRs allow users to access and manage their health information through their smartphones and give them the possibility to make appropriate data available to those who need it (Ouhbi et al., 2015). Unified healthcare systems such as systems that combine EHR and mPHR are considered to be a powerful tool that could facilitate seamless communication between patients and clinicians, leading to faster and informed decisions, that are especially valuable in patients with chronic conditions such as diabetes (Chang et al., 2010; Richardson et al., 2017).

The potential of utilization of PHD towards the creation of more personalized healthcare systems has been discussed in literature (Pagliari et al., 2007; Wilcox et al., 2009; Wilcox et al., 2010). Previous studies have recognized the vital role of personalization features in the design of future healthcare applications as components that could facilitate doctor-patient interaction (Larkin and Kelliher, 2011). For example, the addition of free-text annotation fields to enable storage of personal information of patients to EHR, could provide doctors with essential context pertinent to diagnosis of diseases (Larkin and Kelliher, 2011). Apart from that, the addition of design components to include patients' personal information in electronic healthcare systems has been proposed as a step towards the improvement of quality of care

that potentially could also contribute to cost reduction (Zhou et al., 2010).

Nevertheless, barriers such as security and privacy concerns discourage individuals to exploit this potential in spite of the fact that medical data are under the umbrella of constitutional laws (Srinivasan, 2006; Sahama et al., 2013). In the USA, the current legislation concerning the protection of medical data is regulated by Health Insurance Portability and Accountability Act (HIPAA) since 1996, while in Europe the enforcement of the new General Data Protection Regulation (GDPR) on May 2018, aims to protect processing of personal data and to establish security standards for the distribution of data (Carrión et al., 2011; GDPR, 2016). According to the new GDPR people will have the right to demand and obtain electronic copies of health data from data controllers at no cost, while data sharing will be more transparent in terms of access control and protection of anonymity (GDPR, 2016).

Many international organizations are working on the standardization of e-health applications, particularly EHRs applications (ISO/TR 20514:2005) (iso, b) and PHRs applications (ISO/TR 14292:2012) (iso, a), to address the need for common frames of references. Among the well-know international organizations that work on e-health standardizations: Clinical and Laboratory Standards Institute (CLSI) (Cls, 2018), International Telecommunication Union (ITU-T/ITU-D2) (Itu, 2018), e-health Standardization Coordination Group (eHSCG) (eHS, 2018) and International Organization for Standardizations (ISO) Technical Committee (TC) on health informatics (ISO/TC 215) (Iso, 2018). Their effort demonstrates a continuous demand for establishment of internationally accepted standards for the electronic exchange of medical information including personal health data (PHD).

PHD management is a research topic that has attracted the interest of researchers and practitioners from various disciplines, such as engineers, computer scientists and medical professionals (Puustjärvi and Puustjärvi, 2016; Alyami et al., 2017; Agboola et al., 2017). Various aspects of PHD have been studied and discussed so far, such as mobile-based solutions for integration of PHD to healthcare system, PHD management using meta-data and cloud-computing for seamless access and sharing of data among medical professionals, as well as access control and security of PHD in cloud-computing (Aboelfotoh et al., 2014; Alyami et al., 2017; Li et al., 2010). While privacy and security solutions have also been a subject of discussions (Señor et al., 2012; Ishikawa et al., 2007), many studies have been focused on evaluation of accessing and sharing of PHD.

To the best of our knowledge, no previous studies have reported and mapped accessing and sharing of PHD. Thus, the present paper aims to give an overview of the published research in this topic identifying research gaps and stressing directions for future research. To select candidate studies for this survey of literature, a bibliographic search was conducted in databases such as IEEE Digital Library and ACM Digital Library. The selected papers have been classified afterwards according to their research types, empirical types and contribution types. This paper is based on a previous study on PHD (Karampela et al., 2018b).

The remainder of the paper is organized as follows. Section 2 outlines the research method that was used. Section 3 presents the articles that included in the study and classification results. Section 4 discusses the main findings of the study. Finally, Section 5 presents the conclusions and future work.

2 METHOD

This study has been undertaken as a survey of literature of the articles that address the topics of accessing and sharing of PHD.

2.1 Review and Protocol

Quality reporting guidelines in this paper, specified by the Preferred Reporting Items for Systematic reviews and Meta-Analysis (PRISMA) group (Liberati et al., 2009), were followed. Before beginning the search for studies and the data extraction, a review protocol was developed in which each step was described, including eligibility criteria.

2.2 Eligibility Criteria

The following inclusion criteria (IC) were used:

IC The studies that address PHD.

The studies that met at least one of the following exclusion criteria (EC) were excluded:

EC1 Papers whose subject is non-digital health data.

EC2 Papers that are focusing on other aspects of PHD such as data management and interoperability.

2.3 Identification of studies

To identify the studies to be included in this study, a search has been conducted in January 2018 in the following sources: IEEEXplore, ACM Digital Library,

Springer Link, and Science Direct (Karampela et al., 2018b). Google scholar was also selected to seek grey literature in the field such as white papers and technical reports. The search string used to perform the search in the digital libraries selected was the following: "Personal'"AND "health" AND "data" AND ("electronic*" OR "Digital"). The selection of this search string is in alignment with the scope of the study, as authors wanted to limit the search results to data instead of systems and applications. The search was limited to the title, abstract and keywords of the studies. There was no time frame specified for the literature search.

A total of 16 studies were selected from 246 papers identified. Fig. 1 shows the process of the studies selection. 5 studies were selected for PHD accessibility and 11 studies for PHD sharing.

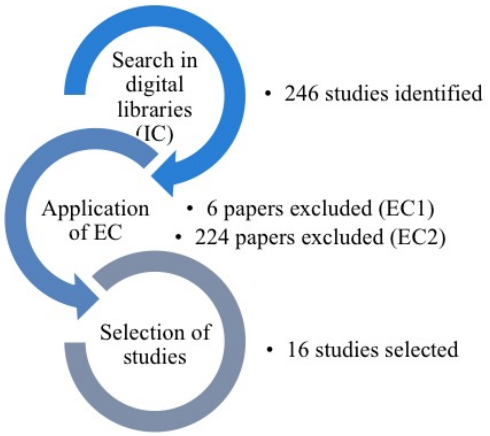

Figure 1: PRISMA Flow Diagram. Acronyms: Inclusion criteria (IC) and exclusion criteria (EC).

2.4 Analysis and synthesis method

The papers selected have been classified with respect of their research type, empirical type and contribution type (Karampela et al., 2018b).

A research type can be classified as:

- Solution proposal: include studies that proposed solutions either new or extensions of an existing approach.
- Evaluation research: the proposed approaches are implemented in practice and evaluation is being performed.
- Opinion paper: these type of papers present a personal opinion pertinent to a solution.
- Other, e.g. Review.

An empirical study could use one of the following empirical methodologies:

- Case study: a study that examines an approach in real-life context.
- Experiment: the evaluation of the approach is performed under controlled conditions.
- Survey: a query to collect qualitative information, e.g. questionnaire.
- History-based evaluation or other: the evaluation of approaches is based on previous results.

If the paper is not empirically evaluated then it is classified as theory.

The type of contribution could be:

- Method: a regular and systematic means of accomplishing PHD.
- Model: a representation of a system that allows investigations through a hierarchical structure.
- Framework: a real or conceptual structure intended to serve as a support or guide for PHD.
- Process: a series of actions, or functions leading to a result and performing operations on data.
- Tool-based technique: a technique based on a software tool to accomplish PHD tasks.
- Guidelines, or other.

The data was tabulated in an Excel Sheet for both quantitative and quality assessment.

3 RESULTS

3.1 Classification results

This section presents the analysis of the results and the map created by combining different facets. The overall result is presented in Table 1.

Fig. 2 shows that there is a discontinuity in the publication trend of PHD accessibility and sharing and also that the interest in both topic has started a decade ago.

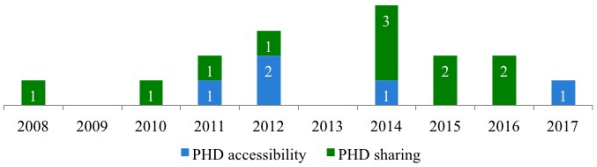

Figure 2: Publication trend

Fig. 3 presents the publication channels that have identified in PHD accessibility and sharing literature. 80% of the selected studies about PHD accessibility are published in journals while 20% are published in

Table 1: Classification results

Topic	Reference	Publication channel	Publication year	Research type	Empirical type	Contribution type
PHD Accessibility	(Wu et al., 2011)	Conference	2011	Solution proposal	Experiment	Method
	(Gladwin, 2012)	Journal	2012	Opinion paper	Theory	Guidelines
	(Van Gorp and Comuzzi, 2014)	Journal	2012	Evaluation research	Experiment	Tool
	(Sulthana and Habeeba, 2014)	Journal	2014	Review	Theory	Method
	(Greenberg et al., 2017)	Journal	2017	Evaluation research	Survey	Tool
PHD Sharing	(Frost and Massagli, 2008)	Journal	2008	Evaluation research	Other	Tool
	(Weitzman et al., 2010)	Journal	2010	Evaluation research	Survey	Model
	(Capozzi and Lanzola, 2011)	Conference	2011	Solution proposal	Experiment	Framework
	(Weitzman et al., 2012)	Journal	2012	Evaluation research	Survey	Model
	(Pickard and Swan, 2014)	Symposium	2014	Solution proposal	Survey	Framework
	(Pickard, 2014)	Conference	2014	Evaluation research	Survey	Method
	(Vahidhunnisha et al., 2014)	Journal	2014	Solution proposal	Theory	Framework
	(Bietz et al., 2015)	Journal	2015	Evaluation research	Survey	Method
	(Ssembatya and Kayem, 2015)	Workshop	2015	Solution proposal	Experiment	Framework
	(Chen et al., 2016)	Journal	2016	Evaluation research	Survey	Method
	(Spencer et al., 2016)	Journal	2016	Evaluation research	Survey	Method

conferences. 64% of the studies selected about PHD sharing are published in journals, 18% in conferences, 9% in symposia and 9% in workshops.

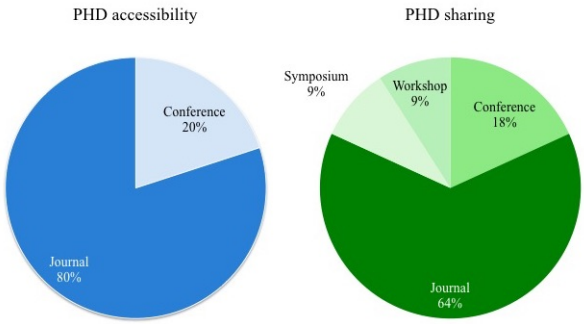

Figure 3: Publication channels

Fig. 4 presents the research types identified in PHD accessibility and PHD sharing literature. The majority of the studies selected are evaluation research, followed by solution proposals.

Fig. 5 presents the empirical types identified in both PHD accessibility and sharing selected studies. The majority of selected studies about PHD sharing are empirically evaluated using surveys or questionnaires, while studies about accessibility have mainly conducted experiments to empirically evaluate their contributions.

Fig. 6 presents the contribution types identified in both PHD accessibility and PHD sharing selected studies. Three types were identified in PHD accessibility: guidelines, tools and methods. While four types are identified in PHD sharing: frameworks, methods, models, and tools.

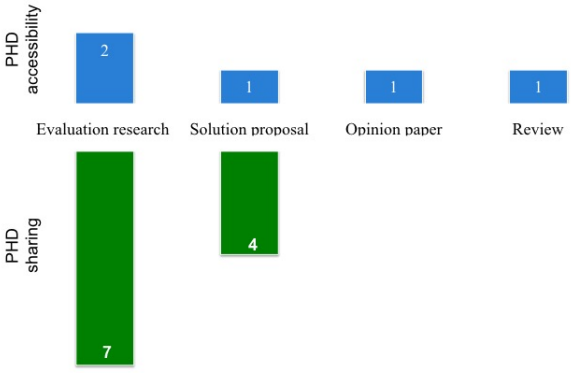

Figure 4: Research types of the selected studies

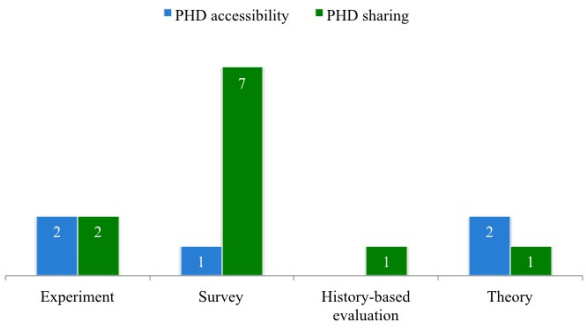

Figure 5: Empirical types of the selected studies

3.2 Solutions for PHD accessibility and sharing

Wu et al. (Wu et al., 2011) have proposed a methodology based on categorized architecture for accessing

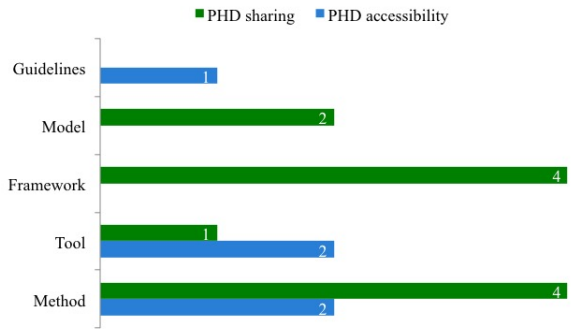

Figure 6: Contribution types of the selected studies

PHRs. The suggested privilege management mechanism allows users to adopt their own privilege scope and access only the required data. The authors argue that their contribution enhances the privacy security level but may have an impact on disease statistics and management of major infectious diseases.

Pickard and Swan (Pickard and Swan, 2014) have presented a framework to increase PHD sharing based on "trust, motivation, community, and informed consent". They have built their contribution on the results of an online survey that has demonstrated a strong willingness to share PHD for research purposes in the population surveyed. Capozzi and Lanzola (Capozzi and Lanzola, 2011) have proposed a synchronization framework for speeding up the implementation of personal health services (PHSs). PHS refers to devices made available by the combination of ICT, microelectronics and nanosciences.

Vahidhunnisha et al. (Vahidhunnisha et al., 2014) have proposed a framework to improve the privacy in sharing PHD in the cloud and to establish patient-centric privacy control over their own PHRs. This framework is based on attribute based encryption (ABE), which is a one to one encryption technique that can be applied to protect PHRs and EHRs. Ssembatya and Kayem (Ssembatya and Kayem, 2015) have also based their contribution on encryption. They have proposed an access control framework supported by identity-based encryption for a secure mPHR system to share PHD in a secure and efficient way.

4 DISCUSSION

4.1 Main findings

This study has conducted a survey of literature concerning accessibility and sharing of PHD. PHD is an interdisciplinary research area with contributions to various disciplines (Larkin and Kelliher, 2011; Li et al., 2014; Mendelson, 2017; Wilcox et al., 2010). The aim of the study was to provide researchers with an overview of the available literature in order to identify limitations in the present published literature. Accessibility and sharing of PHD are research topics that have implications to future design of healthcare systems. Our study points out that research within these topics is still in its infancy.

The interest in PHD accessibility and sharing started since the end of the last decade. This recent interest and the discontinuity in the publication trend may seem reasonable and could be explained by the fact that both topics started to emerge with the use of EHRs, PHRs and digital health.

The majority of papers were published in journals. Despite the increasing interest in accessing and sharing of PHD over the last decade, we only found 16 studies that discuss access and sharing of PHD (5 access, 11 sharing). Regarding access of PHD only one solution proposal was found, which addresses the lack of research in this area.

The contribution types of the selected papers point out a lack of guidelines and tools in both research areas. Thus, more research is needed to towards this direction. The majority of papers concerning sharing PHD were surveys (models, frameworks), suggesting that more experiments are needed. In both research areas no case study has been conducted so far, revealing that there is a lack of user validation on the proposed solutions in real settings.

Although many studies have addressed patients with chronic conditions as the user group that could benefit the most from accessing and sharing of PHD (DuBenske et al., 2010; Kim et al., 2013), only one paper (Greenberg et al., 2017) of the selected studies has evaluated a tool using data from patients with chronic conditions.

4.2 Implications

The findings of this study have implications for researchers who intend to conduct studies pertinent to EHR or in general within PHD subject. In addition, this research is relevant to practitioners who are working in connected health and would like to have an overview on the existent studies on PHD accessibility and sharing. We believe that this study can be a benchmark for future endeavors towards new research in the areas of accessing and sharing PHD, as we have attempted to point out the specific research types and empirical types in need of further research. We invite researchers to direct their research efforts to the suggested areas in order to improve the quality and quantity of research and to offer new perspectives evolving

users more actively in the validation process of the identified approaches.

4.3 Limitations

This study may have several limitations, such as:

- The search was limited only to the title, abstract and keywords of the papers which may have omitted candidate studies. However, if a paper's main focus is PHD then the PHD terms should appear at least in the abstract and keywords which alleviate the risk of omitting relevant studies.
- Other classification criteria may have been relevant to extract further information from the selected studies. However, the main aim of this paper is to give an overview of PHD literature and the criteria used fit this purpose.
- PHD literature was studied mainly in this paper through the engineering and computing lens, for this reason the search for papers was conducted in the databases listed in Section 2.3. Although bibliographic search was conducted in Science and Engineering databases excluding therefore medical libraries such as PubMed, we could argue that the inclusion of Google Scholar, which is a generic database alleviates the risk of omission of relevant studies.

5 CONCLUSIONS

This paper provides an overview of existing research pertinent to PHD accessibility and sharing. We classified the selected papers according to their research type, empirical type and contribution type and then we described in brief the papers included in our study. What we identified is a need for more research about PHD accessibility and for solution proposals for both topics. Although research about accessing and sharing of PHD is still in its infancy, the emergence of connected health solutions (Ouhbi et al., 2018; Carroll et al., 2016) and adoption of wearables technologies could increase scientific interest to this topic in the future. For future work, we intend to propose a solution for PHD accessibility and sharing with which to assist connected health systems designers.

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