
Personal healthcare records research: past, present and new dimensions

Konstantinos Koumaditis*

Department of Business Development and Technology,
Aarhus University, Denmark
Email: kkoumaditis@btech.au.dk
*Corresponding author

Tajammal Hussain

Department of Business Development and Technology,
Aarhus University, Denmark
and
Department of Statistics,
COMSATS Institute of Information Technology,
Lahore, Pakistan
Email: tajammal@ciitlahore.edu.pk

Abstract: When designed and managed properly, personal health records (PHRs) are valuable tools that can reform healthcare systems. Yet while the PHR literature covers multidiscipline cases on design requirements, implementations and early positive results, it also echoes concerns related to the undelivered potential and challenges tied to PHRs. Consequently, a vast body of literature exists with unclear themes and blurred lines between perception, realisation and outcome. This paper exposes dominant research themes in PHR research and aids the understanding of this developing field. Our bibliographic analysis of 524 papers published from 2000 to 2015 revealed a core set of 61 publications. Interesting identified themes include the operation of PHRs with emphasis on innovation, prototypes and governance, as well as the impact of PHRs on specific medical conditions, healthcare processes and sociotechnical issues. Design issues were also exposed focusing on user requirements, design elements and technologies and lessons learned through empirical cases.

Keywords: personal healthcare records; PHRs; medical systems; healthcare technology; lessons learned; bibliometric analysis; multidimensional scaling; MDS.

Reference to this paper should be made as follows: Koumaditis, K. and Hussain, T. (2018) 'Personal healthcare records research: past, present and new dimensions', *Int. J. Healthcare Technology and Management*, Vol. 17, No. 1, pp.1–28.

Biographical notes: Konstantinos Koumaditis is an Assistant Professor at the Department of Business Development and Technology of the Aarhus University in Denmark. He holds a Bachelor on Engineering from the University of Portsmouth UK, Master's degree with specialisation in Electronics, Digital Systems, University of Hertfordshire UK, Master's on Engineering Management with honors from the Brunel University, UK and a

PhD degree from the University of Piraeus, Greece. He participated as a researcher in European and national research projects with focus on: IS, SOA, SOA Governance, HIS. His research interests include amongst other: digital health services, HIS, EHR, SOA, SOA and cloud computing governance, IS and project management.

Tajammal Hussain is serving at the COMSATS Institute of Information Technology, Pakistan, in the capacity of an Assistant Professor. He completed his post-doctorate degree from the Aarhus University, Herning, Denmark. He completed his PhD in Total Quality Management from the Institute of Quality and Technology Management, University of the Punjab, Pakistan. He also holds a Master of Statistics and a Master of Quality Management. He has published on quality management, organisation behaviour, human resource management, project management and advanced statistical methods. Recently, he is working on bibliometric techniques to explore the intellectual structures of existing body of knowledge.

1 Introduction

This research casts light on the past and current personal healthcare records (PHRs) research themes covering the period from 2000 to 2015 and opens a dialogue on the research issues and future endeavours.

PHRs is a rapidly developing area that has become an established research field in the last decade with a dedicated research community and a growing body of literature (Caligtan and Dykes, 2011; Genitsaridi et al., 2015). In this paper, the term ‘PHRs’ refers to the electronic application through which patients access, share and govern their health information in a private, secure and confidential environment (Pagliari et al., 2007). PHRs were essentially created to augment the use and amplify the interoperability of electronic healthcare records (EHRs). While EHR systems function to serve the information needs of healthcare professionals, PHR systems serve both patients and medical professionals. PHRs capture medical data entered by individuals or measured from body sensors and deliver the data to all of the users with access privileges to information and decision-making capabilities related to the care of those individuals. Especially now, m-health technologies (mobile applications, sensors, wearables), acting as PHRs, play a vital role in the education, rehabilitation and monitoring of patients, as they track data such as dietary information, blood indicators, gait, stress, sleep patterns and tremors. They also allow users to register their drug intake to some extent. In fact, our bodies and behaviour have never been more measured and assessed (Lupton, 2013). Every day, vast medical data sets produced by mobile, patient-oriented infrastructures and stored in PHR infrastructures reveal new insights and pave the way for new treatments and methods to improve patient wellbeing (Dohan et al., 2014).

Exploring the PHRs literature, it is possible to distinguish between various fundamental designs for PHRs, ranging from stand-alone to tethered systems with variances related to architecture and functionality (Kaelber and Pan, 2008). In the stand-alone configuration, individuals might create their silo PHR using commercially available

applications and access/store the data through web-based systems (Tang et al., 2006). Even today, despite the availability of digital means, paper-based stand-alone PHRs are still regularly used. In contrast, tethered PHRs serve as a digitised and automated arrangement, the functionality of which is provided by integrating EHR and PHR structures and allowing patients to view their own health information stored in their healthcare provider's systems. Furthermore, in tethered or connected configurations, the PHR system may include additional functionalities allowing patients to request appointments and prescription renewals; even communicating with clinicians or expert systems (e.g., medical chat-bots).

In this evolving PHR eco-system, academics and vendors alike share an interest in the study and exploration of the challenges, design, development, maintenance, management and continuous reconfiguration of PHR systems. From a research perspective, the emphasis resonates in the support PHRs can provide addressing current healthcare challenges, such as the aging of the population; the need for integrated, low-cost healthcare services; the increased utilisation of medical data and homecare; and the self-management of chronic conditions (Ball et al., 2007; Kaelber and Pan, 2008). In the same body of literature, there are researchers raising ethical, legal, clinical, technical and financial concerns, primarily related to the design of PHRs, data governance and the unrealistic expectations attached to such systems (Greenhalgh et al., 2010; Mora, 2012; Wynia and Dunn, 2010). Moreover, the literature reflects a plethora of diverse systems and designs at different stages of adoption and implementation focusing on a narrow or wide audience and having a local or global perspective (Bjørn and Kensing, 2013). All of these approaches synthesise a vast body of literature – a literature reflecting designers' ideas, user-patient requirements, the concerns of regulators, society's ethical views and constraints, academia's desire for knowledge and the vision of unanimous stakeholders for enhanced PHR systems (Reti et al., 2010).

Sharing this growing interest and beginning with the need to comprehend and analyse the body of the PHR literature, we proceeded with a systematic literature research by applying a bibliometric coupling analysis to investigate the issue at hand. Other research options (e.g., meta-analysis) were considered and dismissed due to the validity and bias attached to such methods (e.g., the selection and publication bias or 'the file drawer problem') (Ahn et al., 2012; Sharpe, 1997).

Bibliometric coupling analysis holds numerous advantages. First, the bibliometric coupling analysis provides clear insight into the literature research method, as it clarifies why a specific section of literature is part of the study. This reduces bias, as the researcher does not intervene in the choice of the representative publications (those forming the representative set), as s/he only sets the qualitative constraints (e.g., the number of citations; Waltman et al., 2010). Thus, choosing to apply a bibliographic analysis – a methodology which is well-established yet quite new and undiscovered in the PHR research discipline – enhances the value and originality of this research.

While Section 1 represents the introduction to the research, Section 2 depicts the applied methodology and parameters used. Subsequently, Section 3 analyses the findings from this process, Section 4 contains the discussion, Section 5 presents the multidimensional scaling (MDS) of the data set, Section 6 the conclusions and, finally, Section 7 discusses the limitations of this research.

2 Methodology

The search was based on Elsevier's Scopus database peer-review journal and conference articles published in English from January 2000 to December 2015. We used the keywords 'personal healthcare record' and 'patient-oriented record', focusing exclusively on the title of the publication, as this produces more targeted search results. It is worth mentioning that the keyword search option in more fields (e.g., abstracts and keywords) was also explored and despite a greater volume of publications, the themes and contents of the publications were largely out of scope for this research. The reason is that a keyword section contains at least ten words [e.g., Thygesen et al. (2011)] and an abstract section a text of 300+ words [e.g., Martin et al. 92004) and although the actual search keywords that we set were identifiable (as in the cases of Thygesen et al. and Martin et al.), they were not arranged in consecutive order and therefore did not represent the field under investigation. Therefore, after a recalibration of the keywords search, the focus was placed on the title of the publications exclusively. This process revealed 524 publications spanning a wide range of both dissemination outlets and research interests (illustrated in Section 3), providing a depictive outline of the PHR research. Following the initial literature investigation, we proceeded with the bibliometric coupling analysis described in the next section.

2.1 Bibliographic coupling analysis

Traditionally, researchers explore the intellectual structure of a research field either by a qualitative approach or meta-analysis. Recently, however, bibliometric methods have gained increased appreciation as a prolific technique to understand the knowledge base of a research field, especially if the field is vast and complex to analyse (Acedo et al., 2006; Ramos-Rodríguez and Ruíz-Navarro, 2004; Vogel and Güttel, 2013). This recent interest in bibliometric analysis is attributed to the increasing accessibility of publication databases containing bibliometrics [e.g., citations, co-citations, bibliographic couplings (BGCs)]. As in many other sectors, technical and computational advancement has made it feasible to conduct analyses on very large and complex bibliometric data; data that previously would have been difficult to address with limited resources (i.e., time and human resources).

The BGC used herein is one of the bibliometric methods that identifies the clusters of publications and those linked to each other through the same cited publication (Zupic and Čater, 2015). Originating in the late 60s, this method was introduced by Kessler (1963) to the scientific society through a number of publications and was primarily described as a method for grouping technical and scientific documents, facilitating scientific information provision and document retrieval (Jarneving, 2007). The main principle of BGC is that the number of co-coupled documents defines the strength of links and associations (Boyack and Klavans, 2010; Jarneving, 2007). Following this method, the BGC data is analysed using Bibexcel software to generate a matrix comprised of the BGC frequency (Persson et al., 2009). In order to gauge the strength of the similarities between the publications, Pearson's correlation coefficient matrix is generated from the BGC matrix (Waltman et al., 2010). An advanced multivariate statistical technique of factor analysis is then applied to the correlation matrix to produce clusters (also referred as groups, sets and factors) of publications representing distinct sub-domains of the research field(s).

In our case, the bibliometric database contained 524 PHR publications. These were initially analysed as depicted in Section 3.2 and subsequently processed by Bibexcel software according to the following procedure:

- First, publications were ranked by the number of citations each paper had (at the time of the research) along with details regarding the authors, publication year and journal.
- Secondly, to ensure that the research data to be explored had at least a minimum impact/influence on the field, ranked data were reduced to the number of publications with at least one citation (334 articles). At this point, it is worth clarifying that our investigation aims to reveal the body of literature that shaped trends and inspired the field. The citation constraint decision was taken considering researchers' claims that 90% of all papers published in academic journals are never cited and as many as 50% are never read by anyone other than their authors, referees and journal editors (Lokman, 2007).
- Thirdly, the refined data set (i.e., the 334 articles) was processed by imposing the condition of at least one BGC between the articles. This decision was straightforward, as the unit of analysis was the numbers of BGCs. Publications with zero BGCs holding no analytical value were discarded.
- Fourthly, the BGCs square matrix, comprising R_i rows and C_j columns, was generated. Each corresponding row and column (R_iC_j) in the BGCs square matrix represented two publications where $i \neq j$, while the corresponding values of each i^{th} row and j^{th} column (R_iC_j) showed the number of times the two publications were citing the same reference. For example, the corresponding value against 37th row and 14th column ($R_{37}C_{14}$) was 6, suggesting that these two publications cited six common references.

The BGCs square matrix was then transferred from Bibexcel to an Excel sheet. Here, the unit values in diagonal order were replaced with zeros, as no publication could be cited within itself. Pearson's correlation matrix (PCM) was then generated in Excel. The coefficients of Pearson have revealed the interrelationships between the publications listed in rows and columns; in simple terms, the higher the value of the correlation coefficient, the higher the level of similarity between two publications. A positive correlation coefficient depicted a similarity between the related articles, while a negative value of coefficient depicted a dissimilarity. The findings of this process can be seen in Section 3.2 and are discussed further below.

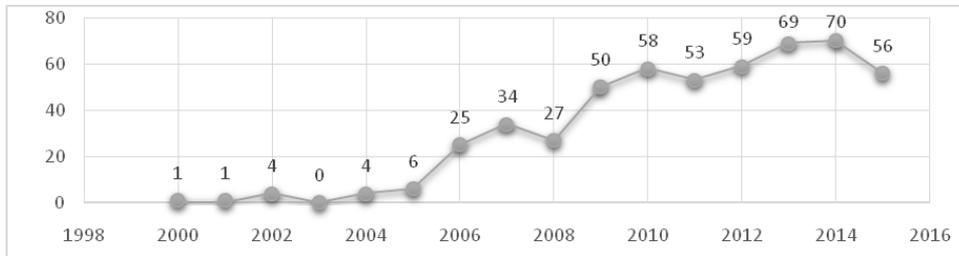
3 Findings

The following section depicts the findings from our analysis. The first part includes the findings from the retrieved main data set of 524 publications, while the second part holds the findings from the factor analysis (i.e., the core data set of 334 publications represented by four factors).

3.1 Findings from systematic literature review

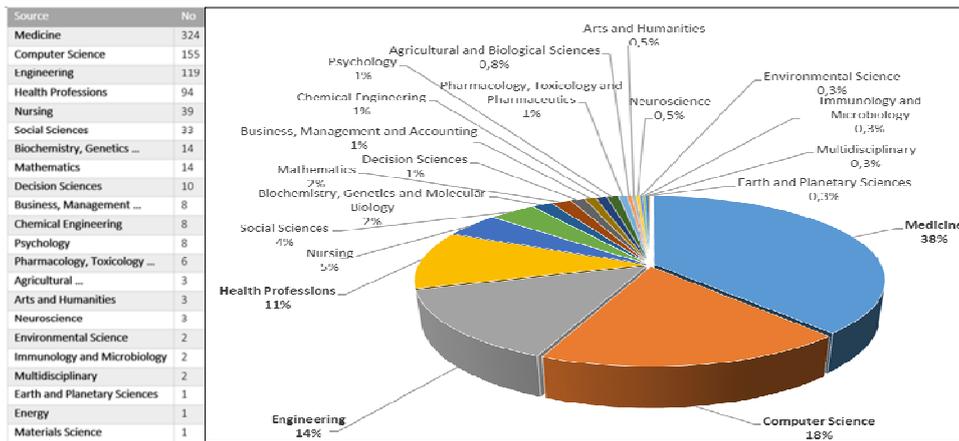
The earliest reference to the term ‘personal health record’ can be tracked to an article indexed by PubMed dated ‘June 1978’ (Britain, 1978). Most scientific articles written about PHRs have been published since 2000, however, making the years 2000 to 2015 the centre of our research (see Figure 1). More specifically, the span of literature identified covers a 15-year period with a relatively healthy growth of publications each year (data from 2016 that are not covered herein present a normalisation of the amount of publications for the year 2015, while some fluctuation exists in years 2003, 2008 and 2011). This interest in PHRs and especially the plethora of publications after 2010, is a concurrent event with the coordinated efforts of integrated healthcare information systems (HIS) through cloud computing and technological advances and the adoption of mobile computing [e.g., m-health; Li et al. (2013) and Seldon et al. (2014)].

Figure 1 Number of PHR publications per year



The findings of the main data set reveal that 57% of the publications hold a medical subject; nursing and health professions follow, with 11% and 7%, respectively. An overview description of the subjects, their actual occurrence in publications and their representation percentages identified in the literature are illustrated in Figure 2.

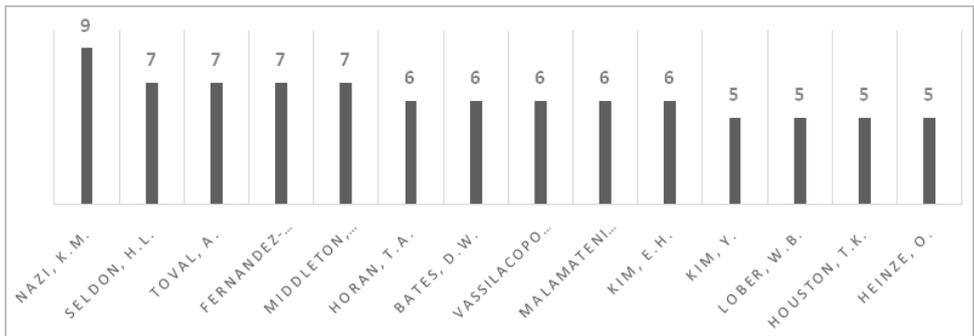
Figure 2 PHR literature distributions over subject areas (see online version for colours)



Notes: a: The categorisation was extracted by records as populated in the Scopus database.
 b: Each publication may hold more than one subject.

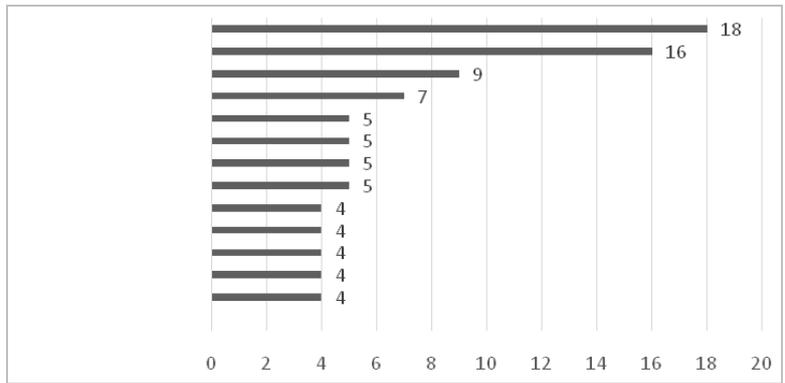
Analysing the data set focusing on the authors with the most publications and narrowing the list (for simplicity) to at least five research papers in the field of PHRs, a set of 14 authors was produced (see Figure 3). Evidently, Dr K. M. Nazi, with nine publications (h index = 12) from the VA Medical Center, Veterans and Consumers Health Informatics Office in the USA, has authored the most publications. The listing in Figure 3 is by no means exhaustive but provides a glimpse of the significant authors in the field, which is further analysed in the following sections.

Figure 3 Authors with high numbers of publications



The descriptive analysis also provided details on the outlets chosen by the authors to disseminate their research, as highlighted in Figure 4. The *International Journal of Medical Internet Research* and the *AMIA Symposium Proceedings*, both outlets that welcome the technology and healthcare themes, hold high places among the set of outlets.

Figure 4 Outlets with frequent number of publications



Source: Journals of PHR research

The affiliations (institution, department, city, country) of the authors were extracted from the RIS file in Bibexcel. For each affiliation, the city in which the organisation is located was extracted for the analysis. The data was further processed using Google’s geographical mapping command in Bibexcel to find the latitude and longitude of each

identified affiliation. Pinpointing the coordinates of the cities and with the GPS Visualiser (<http://www.gpsvisualizer.com>), Figure 5 was produced. Figure 5 depicts the geographical locations of the organisations contributing to PHR literature. The size of the red spheres is proportional to the contribution degree of each organisation. The contributing organisations are concentrated in North America and Europe. In the US, many reported PHR cases are interlinked between prestigious medical schools and initiatives [e.g., veteran affairs (VA) programs]. This finding comes as an addition to the top author list and links the highest ranked (in publications) author with the VA programmes research. These VA initiatives were implemented to assist veterans and soldiers in numerous VA Medical Centers (VAMC) and to aid their rehabilitation and treatment as needed. In Europe, the University of Murcia in Spain, Piraeus in Greece and City in the UK are frequently affiliated with the authors of our data set. Overall, the geographical dispersion of the organisations indicates that PHR research and practice has attracted organisations and research centres from around the globe, although primarily concentrated in North America and Europe.

Figure 5 Geographical location of contributing organisations (see online version for colours)



A commonly utilised investigation method in the bibliometrics arsenal is ‘keywords’ analysis (i.e., keywords provided by the authors of the publications as the most representative of their publication). Such analysis was performed and, as expected, the most frequent keywords identified did not diverge from the keywords used to retrieve the data set of publications explored in this review (i.e., words such as ‘personal’, ‘electronic’, ‘healthcare’, ‘record’). Since this analysis would have provided little real value to the reader, we instead gathered and depicted the most meaningful keywords; that is, keywords beyond the words used to identify the data set. These are seen in Table 1, divided in time periods as 2000–04, 2005–08, 2009–12 and 2013–15, for simplicity. It is worth mentioning that (a) due to the limited number of publications in the early years (e.g., 2001 and 2003 had zero publications), the volume of meaningful keywords was also of limited volume and (b) not all journals included author keywords (e.g., JAMIA Kahn et al., 2010).

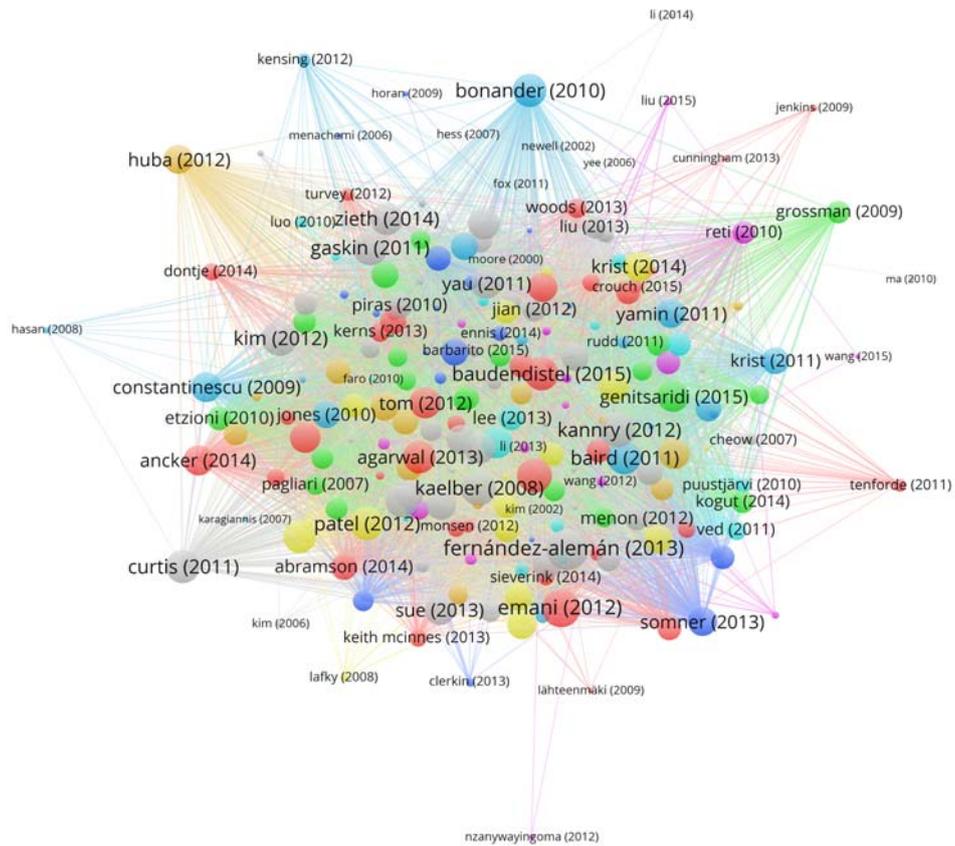
Table 1 Meaningful keywords progression over time

Period	Networks, standards and architecture	Data governance	Use and user	Medical condition	E-health components	Conceptualisation
2013–2015	<ul style="list-style-type: none"> • WBAN • Cloud computing • ISO/IEC 25010 • XDS affinity domain • Clinical document architecture (CDA) • SOA • XML • HIP/AA • HL7 • Meaningful use 	<ul style="list-style-type: none"> • Data privacy • Data stewardship • Ubiquitous access • Anonymous multi-receiver • Identity-based encryption • Cloud computing security 	<ul style="list-style-type: none"> • Usability • Usage patterns • User-centered design • User experience design • Patient empowerment 	<ul style="list-style-type: none"> • Type 2 diabetes mellitus • Coronary artery disease • Cancer • Glaucoma • AIDS/HIV, elderly • Chronic condition • Mental 	<ul style="list-style-type: none"> • Biomedical imaging • Patient portal • Telemonitoring • Mhealth 	<ul style="list-style-type: none"> • Self-determination theory • Discourse analysis • Technology acceptance model (TAM)
2009–2012	<ul style="list-style-type: none"> • ISO/ENI3606 • ISO/IEEE11073 • SSL-VPN • NHIN • XML • HL7 • SOA 	<ul style="list-style-type: none"> • Goal-oriented requirements engineering • Identity-based cryptography • Identity management • Semi-automated capture 	<ul style="list-style-type: none"> • Perceived ease of use (PEOU) • Employer-sponsored PHR 	<ul style="list-style-type: none"> • Hypertension • Mental health • Older • Children 	<ul style="list-style-type: none"> • Medical data visualisation • Medical information systems • Health communication trend • PACS 	<ul style="list-style-type: none"> • Social cognitive theory • Ethics
2005–2008	<ul style="list-style-type: none"> • Web-based healthcare • Multi-agent infrastructure • Computer agents • HIP/AA • Open source • XML • Social networks 	<ul style="list-style-type: none"> • Data sharing, Information protection • Privacy, safety 	<ul style="list-style-type: none"> • Distributed diagnosis and home healthcare (D2H2) • Personal digital assistant communication • Patient-physician language • Digital divide • Patient education, Patient empowerment • Randomised controlled trial 	<ul style="list-style-type: none"> • Self-reporting of subjective symptoms • Palliative care 	<ul style="list-style-type: none"> • Automation in telemedicine • Video telehealth • Information technology 	
2000–2004						<ul style="list-style-type: none"> • Child health record • Consumer health records

Additionally and in order to be easily depicted herein, the keywords were roughly categorised in six descriptive categories:

- a networks, standards and architecture
- b data governance
- c use and user parameters
- d medical condition
- e e-health components
- f conceptualisation (theories beyond PHRs).

Figure 6 Cluster (cloud) of publications with 1cit (see online version for colours)



Note: Created using VOSviewer.

Source: Van Eck and Waltman (2014)

Table 1 thus provides a sense of how the themes changed over time. For example, one might notice how ISO standards started to find their way into the PHR literature from 2009–2012 and more frequently in the 2013–2015 period, as well as a shift from generally designed PHRs towards medical-condition-specific designs more recently (see medical condition category and 2013–2015 period). Thus, while the list is not exhaustive

and the findings require further and deeper analysis, examining the change of keywords provides some initial indications of how the themes changed over time.

To the aforementioned main data set (i.e., the 524 publications), we imposed a qualitative constraint of at least one citation per article and reconfigured the data set resulting in 334 publications (the one citation constraint satisfies a minimum impact/influence of the publication in the PHR field). In the new set, 230 publications were found interlinked with each other and connected by 7,211 connections (the entire set holds 11,526 connections) in eight clusters, as seen in the cluster cloud in Figure 6. The relative size of each publication (diameter of sphere symbol) is significant and depicts its linkage strength. For example, Emani (2012) in the bottom right of the cluster has greater linkage strength than Somner (2013), who is part of the same cluster.

The visual representation of such a vast data set cannot enhance our understanding of the PHR research, as the publications are tightly interwoven and the links between them are abundantly present. As mentioned in the methodology section, we therefore preceded with a factor analysis and a clearer representation of the research trends. The description of this process and the resulting findings are the subject of the next section.

3.2 Findings from the factor analysis

A bibliometric co-coupling matrix was extracted from the Scopus data set by using the Bibexcel software (Persson et al., 2009). The generated co-coupling matrix was further converted into a correlation bibliographic co-coupling matrix and stored as an Excel sheet (a process described in detail in Section 2.1).

Table 2 Findings from the FA with items and factor loadings

Component	Total variance explained		
	Rotation sums of squared loading		
	Total	% of variance	Cumulative %
1	26.557	37.405	37.405
2	8.909	12.548	49.953
3	6.076	8.558	58.511
4	5.130	7.225	65.736

The next step was to develop clusters (referred from hereon as factors, since we utilised the factor analysis method) containing publications contributing to a common knowledge base in the field. To do so, a statistical package for data analysis (i.e., SPSS 20), was utilised as a software solution and the principal component analysis (PCA) as a methodology. From a technical perspective, the main PCA settings applied to define the factors to be extracted were: Varimax as a rotation method, rotated solutions, Kaiser’s criterion (default option for varimax rotation) and scree plot (single visual representation available). Without going into technical detail, it is worth mentioning that the Varimax option (instead of Equamax, Promax, or Direct Oblimin) was chosen after testing the alternatives (Varimax produced more ‘readable’ outcome) and rotation method instead of unrotated in order to obtain a higher degree of organised data (for further technical details, one might seek inspiration in similar approaches, like Annarelli and Nonino (2016), Di Stefano et al. (2010) and Jarneving (2007)).

Table 3 Findings from the FA with individual items and their factor loadings

<i>Authors</i>	<i>MDS</i>	<i>Factor loading</i>				<i>No of cit.</i>
		<i>F1</i>	<i>F2</i>	<i>F3</i>	<i>F4</i>	
Househ et al. (2014)	P280	.968				001
Hudson and Cohen (2008)	P109	.968				008
Seldon (2014)	P276	.967				001
Bonander and Gates (2010)	P055	.967				020
Clerkin et al. (2013)	P229	.966				002
Seldon et al. (2014)	P277	.966				001
Li et al. (2013)	P003	.966				152
Li et al. (2010)	P015	.966				052
Gu and Day (2013)	P184	.965				003
Wang et al. (2013)	P185	.964				003
Genitsaridi et al. (2013)	P190	.964				003
Weitzman (2010)	P034	.964				026
Buckley et al. (2011)	P065	.964				015
Wang et al. (2012)	P161	.963				004
Liu et al. (2011)	P072	.963				013
Fetter (2009a)	P150	.962				005
Ozok et al. (2009)	P315	.962				001
Hudson and Cohen (2010)	P131	.962				006
Fetter (2009b)	P203	.962				003
Genitsaridi et al. (2015)	P271	.962				001
Baird et al. (2011)	P129	.962				006
Grant et al. (2008)	P007		.859			094
Roblin et al. (2009)	P010		.847			078
Yamin et al. (2011)	P009		.843			086
Krist et al. (2014)	P113		.837			007
Britto and Wimberg (2009)	P078		.829			013
Kogut et al. (2014)	P137		.826			005
Bourgeois et al. (2008)	P023		.741			038
Baudendistel et al. (2015)	P273		.729			001
Gaskin et al. (2011)	P165		.661			004
Kaelber et al. (2008)	P001		.649			191
Piras and Zanutto (2010)	P069			.464		014
Krist et al. (2011)	P052			.470		020
Curtis et al. (2011)	P239			.498		002
Nazi (2010)	P017			.483		045
Sue et al. (2013)	P223			.500		002

Note: MDS refers to the MDS matrix depicted in Section 5

Table 3 Findings from the FA with individual items and their factor loadings (continued)

<i>Authors</i>	<i>MDS</i>	<i>Factor loading</i>				<i>No of cit.</i>
		<i>F1</i>	<i>F2</i>	<i>F3</i>	<i>F4</i>	
Patel et al. (2012)	P051			.475		020
Abramson et al. (2014)	P178			.507		003
McInnes et al. (2011)	P240			.406		002
Yau et al. (2011)	P053			.521		020
Tom et al. (2012)	P060			.512		017
Menon et al. (2012)	P235			.431		002
Kahn et al. (2010)	P035			.493		026
Reti et al. (2010)	P020			.419		041
Kannry et al. (2012)	P125			.510		006
Emani et al. (2012)	P037			.532		025
Wagner et al. (2012)	P021			.308		040
Walton and Bedford (2007)	P134			-.522		006
Hampshire et al. (2004)	P083			-.482		012
Kerns et al. (2013)	P139			.452		005
Wright et al. (2006)	P118			-.412		007
Puustjärvi and Puustjärvi (2010)	P167			-.388		004
Puustjärvi and Puustjärvi (2009)	P253			-.388		002
Somner et al. (2013)	P289			-.361		001
Pai et al. (2013)	P183				.851	003
Do et al. (2011)	P044				.825	023
Caligtan and Dykes (2011)	P057				.816	018
McInnes et al. (2013)	P084				.779	011
Haggstrom et al. (2011)	P042				.651	024
Tsai and Rosenheck (2012)	P048				.466	021
Reeve et al. (2013)	P228				.369	002

Note: MDS refers to the MDS matrix depicted in Section 5

In our case, the number of factors extracted was four, as seen in Table 2 (with the first holding $\approx 37.4\%$, the second $\approx 12.5\%$, the third $\approx 8.5\%$ and the fourth $\approx 7.2\%$ of the total).

We have opted for the fixed number (i.e., four factors), since the scree plot suggested a distribution of 70 factors, with each factor after the fourth having a relatively small contribution in explained percentage of variance ($< 2.3\%$). The PCA thus yielded a set of four factors in 61 publications (65.736% explained variance). As each further incremental factor explained an insignificant variance and in order to perform a cohesive analysis, we therefore retained these four factors only. Table 3 provides the core representative set of pattern matrix, which comprises correlation coefficients associated with each publication.

Table 4 FA of the operation of PHRs

<i>Authors</i>	<i>Description</i>	<i>Type of research</i>	<i>Geographical area</i>	<i>Medical interest/care</i>
Househ et al. (2014)	Meaningful use	Conceptual	USA	-
Hudson and Cohen (2008)	Temporal trend analysis	Conceptual	Worldwide	Cardiac
Seldon (2014)	Prototype mobile PHR	Conceptual	Asia	-
Bonander and Gates (2010)	Opportunities and innovations	Conceptual	USA	Public health
Clerkin et al. (2013)	Personal data	Case study	Ireland	Gen. practice
Seldon et al. (2014)	Prototype mobile PHR	Conceptual	Asia	-
Li et al. (2013)	Data encryption	Conceptual	-	-
Li et al. (2010)	Access control framework	Conceptual	-	-
Gu and Day (2013)	PHR use	Case study	New Zealand	Chronic cond.
Wang et al. (2013)	Encryption prototype	Experimental	China	-
Genitsaridi et al. (2013)	Functional evaluation	Review study	-	-
Weitzman (2010)	Medical data sharing	Mix. methods	UK	-
Buckley et al. (2011)	Use of data for research	Mix. methods	Ireland	Gen. practice
Wang et al. (2012)	Encryption prototype	Experimental	China	-
Liu et al. (2011)	Usability evaluation	Study	USA	-
Fetter (2009a)	PHR fundamental theory	Review study	USA	Mental health
Ozok et al. (2009)	Use and user acceptance	Study	USA	-
Hudson et al. (2010)	Data analysis	Conceptual	-	Lab/em. room
Fetter (2009b)	Conceptual analysis	Conceptual	USA	Nursing
Genitsaridi et al. (2015)	Functional evaluation	Review study	-	-
Baird et al. (2011)	Dr-patient interaction	Survey	USA	-

3.2.1 Factor analysis

The core representative set of 61 publications divided into four factors was explored for common themes and patterns. Consistent with prior studies exploring factor and cluster

analysis techniques, the factors were labelled studying each publication, but focusing on the title, keywords, abstract, discussion and concluding parts of each paper and taking under consideration the research areas, themes, sub-themes, findings and concluding remarks of each publication (Annarelli and Nonino, 2016; Fahimnia et al., 2015). The outcome was four factors that were described individually by analysing the representative publications of each group, namely (F1) operation of PHRs: innovations, prototypes, data governance challenges and PHR research implications, (F2) the impact of PHRs on: medical conditions, healthcare processes and sociotechnical issues, (F3) the design of PHRs: user requirements, elements and technologies and (F4) PHR practise: lessons learned and challenges.

3.2.2 (F1) operation of PHRs: innovations, prototypes, data governance challenges and PHR research implications

The first factor (F1) includes 21 publications spanning from 2008 to 2015, with the majority of cases originating from the US and with few examples from Asia and Europe, as seen in Table 4. The authors in this set present PHR innovations and prototypes [e.g., Bonander and Gates (2010), Seldon (2014) and Seldon et al. (2014) and address function and research issues on data safety and security, such as encryption [e.g., Li et al. (2013) and Wang et al. (2012)], medical data sharing and access control [e.g., Li et al. (2010) and Weitzman et al. (2010)]. An interesting sub-theme also discusses attitudes among the public and patients towards the use of PHR data for health research (Buckley et al., 2011; Clerkin et al., 2013).

Table 5 FA of PHRs’ impact

<i>Authors</i>	<i>Description</i>	<i>Type of research</i>	<i>Geographical area</i>	<i>Medical interest/care</i>
Grant et al. (2008)	PHR impact on treatment	Experimental	USA	Diabetes
Roblin et al. (2009)	Patient access to PHR	Study	USA	-
Yamin et al. (2011)	PHR adopters	Stat. analysis	USA	-
Krist et al. (2014)	PHR users	Mix. methods	USA	Primary care
Britto and Wimberg (2009)	Customised PHR	Conceptual	USA	Paediatrics
Kogut et al. (2014)	PHR impact on medication	Study	USA	Medication
Bourgeois et al. (2008)	Patient control to PHR	Conceptual	USA	Paediatrics
Baudendistel et al. (2015)	User requirements	Case study	Germany	Cancer
Gaskin et al. (2011)	Sociotechnical issues	Case study	USA	-
Kaelber et al. (2008)	Research issues	Review	-	-

Table 6 FA of PHRs' design

<i>Authors</i>	<i>Description</i>	<i>Type of research</i>	<i>Geographical area</i>	<i>Medical interest/care</i>
Piras and Zanutto (2010)	PHR design	Case study	Italy	-
Krist et al. (2011)	Preventive care	Case study	USA	Primary care
Curtis et al. (2011)	Comparisons and analysis	Study	Canada	-
Nazi (2010)	User requirements	Survey	USA	-
Sue et al. (2013)	PHR features usage	Study	USA	-
Patel et al. (2012)	User requirements	Survey	USA	-
Abramson et al. (2014)	PHR functionalities	Survey	USA	-
McInnes et al. (2011)	Electronic outreach	Case study	USA	AIDS/HIV
Yau et al. (2011)	Physicians perspectives	Case study	Canada	Primary care
Tom et al. (2012)	Parent-reported experiences	Survey	USA	Paediatrics- chr.dis.
Menon et al. (2012)	Patient and physician attitudes	Survey	USA	Emergency dep.
Kahn et al. (2010)	Patients' interaction	Experimental	USA	AIDS/HIV
Reti et al. (2010)	Improvements analysis	Study	USA	-
Kannry et al. (2012)	Meaningful use	Review	USA	-
Emani et al. (2012)	Patient perceptions	Study	USA	-
Wagner et al. (2012)	User expectations	Case study	USA	Hypertension
Walton et al. (2007)	Parents' expectations	Survey	UK	Paediatrics
Hampshire et al. (2004)	Personal child health record	Survey	UK	Paediatrics
Kerns et al. (2013)	Patients' engagement	Case study	USA	Primary care
Wright et al. (2006)	Personal child health record	Study	UK	Paediatrics
Puustjärvi and Puustjärvi (2010)	PHR design	Conceptual	Finland	-
Puustjärvi and Puustjärvi (2009)	PHR design	Conceptual	Finland	-
Sommer et al. (2013)	Design aspects	Case study	UK	Glaucoma

3.2.3 (F2) the impact of PHRs: on medical conditions, healthcare processes and sociotechnical issues

Factor 2 (F2) includes ten articles published from 2008 to 2015 and addresses the impact of PHRs on cases mainly from the USA (see Table 5). In this set, the researchers depict the effect of PHRs on the treatment of specific medical conditions like diabetes (Grant et al., 2008) and cancer (Baudendistel et al., 2015), processes like medication (Kogut et al., 2014), or on healthcare costs (Kaelber et al., 2008) and other sociotechnical issues like teamwork, accountability and vendor-customer coordination (Gaskin et al., 2011). The effects of PHR system adoption and diverse user profiles (Roblin et al., 2009; Yamin et al., 2011) were also reported in this group of publications.

3.2.4 (F3) PHRs' design: user requirements, elements and technologies

Factor 3 (F3) includes 23 articles from 2004 to 2014, mainly from the US, but also including cases from the UK, Canada, Italy and Finland, as seen in Table 6. Publications in this set address the design of PHR systems, focusing on the user requirements, where the user is either the patient, the physician, or the guardian of a child [e.g., personal child health record (PCHR)]. In more detail, the PHR design is explored from a user-requirement perspective [e.g., Emani et al. (2012) and Wagner et al. (2012)], from a physician as a PHR user aspect [e.g., Menon et al. (2012) and Yau et al. (2011)] and from design elements and technological views [e.g., Puustjärvi and Puustjärvi (2010) and Sue et al. (2013)]. Moreover, three cases deal with a UK PCHR and the parent's (main user) requirements (Hampshire et al., 2004; Walton and Bedford, 2007; Wright and Reynolds, 2006). Interestingly enough, although the aforementioned research investigates the user requirements and processes involved with a non-electronic record at the time of publication, an online fully functional version of the PCHR has since been implemented (eRedbook, 2016).

3.2.5 (F4) PHR practise: lessons learned and challenges

Factor 4 (F4) constitutes research that documents the experiences gained working with PHR systems and/or solving a real-world problem. This set includes seven articles published from 2011 to 2013 with cases from the USA, Canada and Australia (see Table 7). The amount of available literature is not vast, yet distinctive recommendations based on analysed knowledge from which others can learn in order to improve their PHR proposition are clearly present. For example, experiences with PHR systems in relation to patients with chronic diseases like cancer (Pai et al., 2013) and AIDS/HIV (McInnes et al., 2013) or specific medical settings and systems like the military (Do et al., 2011) and comparison studies between users (Tsai and Rosenheck, 2012) are depicted. This set also includes cases offering insight into PHR challenges, such as accuracy and synchronisation of data (Reeve et al., 2013). These systems are very relevant to the challenges of PHRs, as they need to integrate, categorise and display medical data from various sources and HIS; HIS that are already prone to errors. In this respect, Haggstrom et al. (2011) reflect on the usability challenges identified especially with older users and pinpoints issues of confidentiality (e.g., on-screen display of medication information) and ease of use (e.g., minimisation of jargon, manual input, lack of graphics) as main findings.

Table 7 FA of PHR practise

<i>Authors</i>	<i>Description</i>	<i>Type of research</i>	<i>Geographical area</i>	<i>Medical interest/care</i>
Pai et al. (2013)	Patient response	Survey	Canada	Cancer
Do et al. (2011)	Pilot project in military	Case study	USA	-
Caligtan and Dykes (2011)	PHR developments	Review	USA	-
McInnes et al. (2013)	User training	Mix. methods	USA	AIDS/HIV
Haggstrom et al. (2011)	Usability assessment	Case study	USA	-
Tsai and Rosenheck (2012)	Comparison study	Study	USA	Mental health
Reeve et al. (2013)	PHR initial results	Study	Australia	-

4 Discussion

Applying the FA in such a vast and interwoven literature segment (i.e., 334 publications) provides a distinctive analytical lens into the past, current and future dimensions of PHR research. Through our analysis, it was observed that the majority of the cases resonated in the USA (34/61 publications) and Europe (10/61 publications), providing more regional than global perspectives. This result is not greatly different to the findings displayed in Figure 5, placing Western countries in the lead in the publication count.

Focusing on the factors themselves and the overall number of citations that each group holds, one might also list them in order of the most citations: F2 (517 cit.), F1 (326 cit.), F3 (322 cit.) and F4 (102 cit.). Observing the number of citations, one can reflect on the accumulated maturity and contribution of each factor, concluding that F2 includes a more mature content (a higher overall citation count) and has thus influenced the PHR field more than, for example, F4. Nevertheless, examining the content of each group more closely reveals a heterogeneous spread of citations inside the factors, with only a few publications holding the majority of citations rather than a balanced number of citations in each publication. In more detail, at the top of the list, F2 holds 517 citations, but the majority of them (487 cit.) come from 50% of the publications contained in the F2 group. Similarly, F1 holds 326 citations, the majority of which (265 cit.) derive from only 10% of the publications of the group. The same for F3 with 322 citations, where the majority (254 cit.) derive from 40% of the publications, while F4 with 102 citations seems more homogeneous, with most (97 cit.) deriving from almost 80% of the publications. Thus, if a researcher studying the PHR field transfers the focus on the number of citations (e.g., maturity/influence) of each factor, special attention may be drawn to F2 and highly cited publications like Kaelber et al. (2008) and Grant et al. (2008) or F1 with frequently cited publications like Li et al. (2010, 2013).

An interesting issue that seems to capture the attention of numerous researchers in the PHR field is the existence of ‘value’ in the use of PHRs. A value that can be distinguished as either:

- a the automation and digitisation of patient-doctor interaction (e.g., the user orders a repeat prescription) and medical data management (e.g., store, review laboratory results, medicines list, etc.)
- b an additive value in the treatment and self-management of medical conditions. In the latter, researchers investigate if a condition-tailored PHR system (e.g., PHR for diabetes patients) will have an effect on the patient's self-management, treatment and outcome of their chronic condition.

Analysing this stream of inquiry, it was identified that only 12 publications of our core representative set exclusively focused on PHRs designed for users with an explicit medical condition [e.g., 'Cancer' by Pai et al. (2013)]. From these, examples of positive results were even more scarce, yet accounted for [e.g., research on diabetes patients utilising PHR functionalities to better control their medication treatment; Grant et al. (2008)] and medication adherence for HIV/AIDS treatment (McInnes et al., 2013). In other words, the medication compliance topic uncovered in our findings is a long-standing challenge for chronic disease treatment and an unresolved issue in the research agenda (Brown and Bussell, 2011). The association of PHRs comes as no surprise to be associated with positive results on the medication compliance issue. If adopted properly, PHRs are designed to offer an automated, relatively accurate and personalised way to maintain a medication management plan; either way, it is the patient who controls the levels of adherence and PHR can only be a supportive mechanism. In the near future, however, it is expected that more PHR cases focusing on the medical adherence challenge will surface as more patients incorporate a PHR in their chronic disease treatment.

Moreover, the majority of our representative cases reflect on a general user-patient, non-condition-specific view [e.g., Emani et al. (2012)]. This can be partially attributed to:

- a the immaturity of the field dealing with the PHR design in a broad way
- b the complexity of the design of the PHRs.

In the latter, Toscos et al. (2016) report on the complexity and challenges of such design (e.g., the patient-condition-centred design) and the difficulties in sustaining accessibility adequately, including technical support elements and requiring minimum training for the use of a PHR (Baudendistel et al., 2015).

Yet while empirical findings showing positive outcomes from extensive (in user volume) PHR use are scarce, research linking the intent to adopt PHRs to treat medical conditions is more frequent. For example, a high percentage of parents of children with chronic diseases appear willing to use an integrated PHR to address their child's healthcare needs (Tom et al., 2012) – and pharmacists to use a PHR designed for homecare patients in order to enhance their ability to identify and resolve medication-related problems and prevent rehospitalisation (Kogut et al., 2014).

Despite increasing internet availability, smartphone use and m-health rise, the literature highlights the challenges that continue to exist between diverse populations. In more detail, literature from our data identifies racial/ethnic minority patients adopting a PHR less frequently and patients with the lowest annual income using a PHR less often than those with higher incomes (Roblin et al., 2009; Yamin et al., 2011). In response to this challenge, many researchers unsurprisingly suggest that training can be of great value. More specifically, the literature indicates that the group training of vulnerable

patients together with outreach to the less educated and computer illiterate is a cost-effective method to increase PHR skills and adoption. This would also improve patient confidence in finding health-related information, making online health-related transactions and interacting with healthcare providers (McInnes et al., 2013; Patel et al., 2012; Wagner et al., 2012). Thus, simply providing a PHR may have limited impact on patients, empowerment, satisfaction with care, or use of health services without additional education or clinical intervention (Wagner et al., 2012).

The literature also indicates a willingness amongst physicians to adopt PHRs under specific circumstances (the patients' illness severity and PHR ability to transmit information of high quality). In hospitals participating in such initiatives, the PHR system relates particularly to more severely ill patients and is enveloped by efficient and securely transmitted communication (Menon et al., 2012; Nazi, 2010).

An interesting finding in our analysis is the discussion raised by researchers in Ireland regarding the attitudes of the public and patients towards the use of PHR data for health research (Buckley et al., 2011; Clerkin et al., 2013). Early PHR adopters would appear to be more willing to share their medical data for research (Weitzman et al., 2010). Nevertheless, the willingness to share was conditioned by anonymity, research use, engagements with a trusted intermediary, transparency around PHR access and use, as well as payment.

Supplementary to the aforementioned research and in our own experiences with m-health research and the exponential growth of medical data, the issues of PHR data governance (e.g., ownership, usage, ethics) are and will remain one of the top issues in the research agenda (Koumaditis, 2015; Koumaditis et al., 2013).

5 Multidimensional scaling

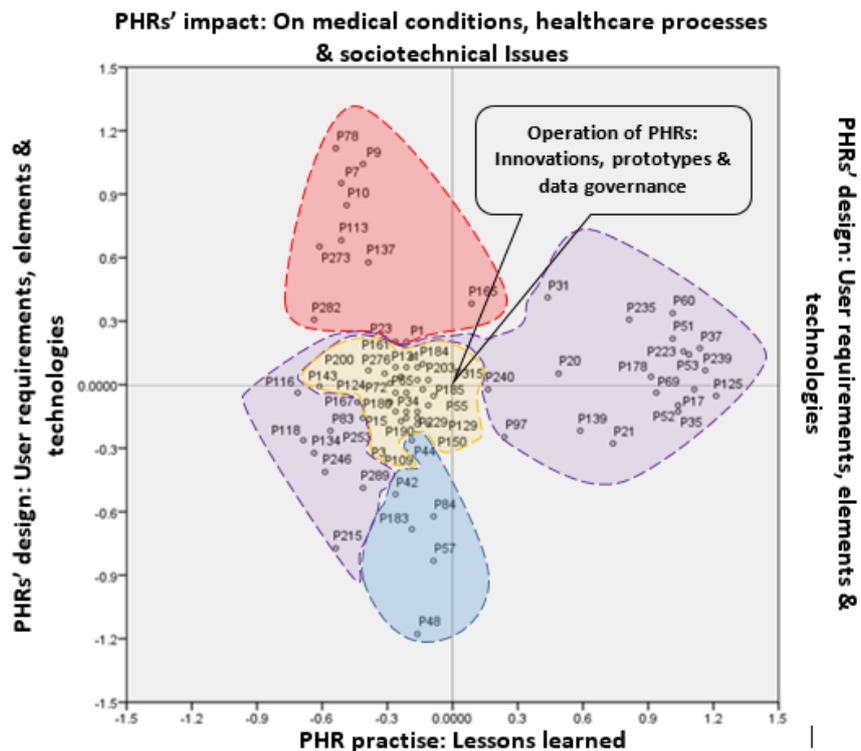
Moving towards a supplementary method to triangulate our analysis, a MDS map was plotted. An MDS is a graphic depiction that represents conceptual proximity, or similarity, between publications. The value of such depictions is to provide a visual representation of a complex set of relationships that can be scanned at a glance. Since maps on paper are two-dimensional, this translates technically to finding an optimal configuration of points in a two-dimensional space. Using Pearson's correlation coefficients, the PHR dataset investigated herein was transformed in an MDS (see Figure 7).

To interpret an MDS map, one must look for clusters and dimensions. In our case, clusters (i.e., factors) were already formed during the FA and depicted on a map by colour coding and encased by dashed lines. This was possible, as the configuration of the points representing the publications in two dimensions (e.g., P7, P28, etc.) was not distorted, providing a clear, visual result. Additionally, following similar MDS analyses [e.g., Annarelli and Nonino (2016)], the borders of the map were given the below-mentioned representative titles:

- Given its proximity to (F2), the top border was entitled 'PHRs' impact: on medical conditions, healthcare processes and sociotechnical issues'. At the top of the map, for example, the Britto and Wimberg (2009) study portrays the current trends and key challenges of paediatric PHRs and how these systems have influenced the paediatrics discipline.

- The bottom border, which is closer to publications from (F4), was entitled ‘PHR practise: lessons learned and challenges’. In the lower part of the map, for instance, one finds the Tsai and Rosenheck (2012) study, which examines internet use among veterans in general and in particular the use of online health information among VA patients. This study depicts lessons learned specifically from the perspective of mental health service users.
- The left and right borders are named after (F3), namely ‘PHRs’ design: user requirements, elements and technologies’. On both sides of the map, research like Wright and Reynolds (2006) addresses the design of PHRs as educational tools, while Kannry et al. (2012) reflect on the design requirements of PHRs for ‘meaningful use’.
- The publications from (F1) are mainly gathered in the centre of the map; hence, it was entitled ‘operation of PHRs: innovations, prototypes, data governance challenges and PHR research implications’. For example, Weitzman (2010) reflects on the data stored in a PHR and investigates the attitudes toward managing and sharing PHR information for research purposes.

Figure 7 MDS depicting eight clusters and their proximities (see online version for colours)



Observing the MDS in terms of the proximities, there is a high concentration of publications in the middle of the map. The close proximity between these publications as a group are associated with one factor (i.e., F1); thus, no further indications (than those

reported for F1) can be reported. In such cases, further investigation usually replotting a new MDS with only the data under question (e.g., F1) can provide a better understanding. Nevertheless, another distinctive concentration of 11 publications (P69, P52, P239, P17, P223, P51, P53, P60, P35, P125, P37) with close proximities can be seen on the right side of the map (part of F3). The publications in this sub-group share more in common than the overarching title of F3 declares (i.e., PHR design). Closely investigating their titles, abstracts and keywords, we find that an interesting aspect is discussed, designing PHRs as a distinctive infrastructure for cooperative work between patients and medical professionals; PHR design that engages patients (Krist et al., 2011), intersects organisational settings and extends (from healthcare-medical) into domestic environments (Piras and Zanutto, 2010). Under this sub-theme, one may discover best practices and features (Curtis et al., 2011; Sue et al., 2013), consumer attitudes and perceptions (Emani et al., 2012; Nazi, 2010) and use patterns (Tom et al., 2012). The sub-theme, however, was not identifiable with our FA analysis and its discovery here demonstrates the value of the MDS as a supplementary tool for investigation.

6 Conclusions

The aim of this research was to formulate a deeper, more profound understanding of PHR systems as a valuable research field and to describe the status of past, current and future research through an analysis. Our analysis started by investigating the period from 2000 to 2015. The data were analysed in relation to their publication year (Figure 1), subject area (Figure 2), researchers (Figure 3), publication outlet (Figure 4) and contributing organisation (Figure 5), thus providing a clear overview of the topic. Additionally, with the utilisation of an advanced bibliometric analysis method, we provided a core representative data set of PHR research (Table 3).

Nevertheless, the novelty of this research derives from the findings of the explorative-focused analysis of the representative data set (61 publications), which revealed interesting facts about PHR as a developing research field. Our FA identified four core groups of research from user requirements to technical design aspects, impact and lessons learned. We also included indicators regarding the geographical setting and medical topics to which they refer. Consequently, considering our approach in terms of the FA, the findings, the discussion and the indicators, a good understanding of the current PHR research field and the trends driving it is achieved. Complementary to our analysis, the MDS matrix (Figure 7) and the close proximities of the publications belonging to the same factor demonstrated our cohesive analysis of PHR research.

7 Research limitations

This research is not immune to the limitations of bibliometric studies. The bibliometric coupling method employed, although fruitful for producing factors and contributing to an understanding of the current literature, as illustrated herein, is not the only available method. Other methods, such as co-citation analyses, may result in different configurations of the same dataset. Additionally, providing different constraints (keywords, one citation, one coupling) may add or subtract data (e.g., publications) and formulate a different basis for analysis than the one used in this research. These

limitations form research issues that can be addressed in follow-up reviews in the near future.

References

- Abramson, E.L., Patel, V., Edwards, A. and Kaushal, R. (2014) 'Consumer perspectives on personal health records: a 4-community study', *American Journal of Managed Care*, Vol. 20, No. 4, pp.287–296.
- Acedo, F.J., Barroso, C. and Galan, J.L. (2006) 'The resource-based theory: dissemination and main trends', *Strategic Management Journal*, Vol. 27, No. 7, pp.621–636.
- Ahn, S., Ames, A.J. and Myers, N.D. (2012) 'A review of meta-analyses in education', *Review of Educational Research*, Vol. 82, No. 4, pp.436–476.
- Annarelli, A. and Nonino, F. (2016) 'Strategic and operational management of organizational resilience: current state of research and future directions', *Omega*, Vol. 62, No. C, pp.1–18.
- Baird, A., North, F. and Raghu, T.S. (2011) 'Personal health records (PHR) and the future of the physician–patient relationship', *Paper presented at the ACM International Conference Proceeding Series*.
- Ball, M.J., Smith, C. and Bakalar, R.S. (2007) 'Personal health records: empowering consumers', *Journal of Healthcare Information Management*, Vol. 21, No. 1, pp.76–86.
- Baudendistel, I., Winkler, E., Kamradt, M., Langst, G., Eckrich, F., Heinze, O. and Ose, D. (2015) 'Personal electronic health records: understanding user requirements and needs in chronic cancer care', *Journal of Medical Internet Research*, Vol. 17, No. 5, e121.
- Bjørn, P. and Kensing, F. (2013) 'Special issue on information infrastructures for healthcare: the global and local relation', *International Journal of Medical Informatics*, Vol. 82, No. 5, pp.281–282.
- Bonander, J. and Gates, S. (2010) 'Public health in an era of personal health records: opportunities for innovation and new partnerships', *Journal of Medical Internet Research*, Vol. 12, No. 3, e33.
- Bourgeois, F.C., Taylor, P.L., Emans, S.J., Nigrin, D.J. and Mandl, K.D. (2008) 'Whose personal control? Creating private, personally controlled health records for pediatric and adolescent patients', *Journal of the American Medical Informatics Association*, Vol. 15, No. 6, pp.737–743.
- Boyack, K.W. and Klavans, R. (2010) 'Co-citation analysis, bibliographic coupling, and direct citation: which citation approach represents the research front most accurately?', *Journal of the American Society for Information Science and Technology*, Vol. 61, No. 12, pp.2389–2404, DOI: 10.1002/asi.21419.
- Britain, G. (1978) 'Computerisation of personal health records', *Health Visit*, Vol. 51, No. 6, p.227.
- Britto, M.T. and Wimberg, J. (2009) 'Pediatric personal health records: current trends and key challenges', *Pediatrics*, Vol. 123, No. 2, pp.S97–S99, DOI:10.1542/peds.2008-1755I.
- Brown, M.T. and Bussell, J.K. (2011) 'Medication adherence: WHO cares?', *Mayo Clinic Proceedings*, Vol. 86, No. 4, pp.304–314, DOI: 10.4065/mcp.2010.0575.
- Buckley, B.S., Murphy, A.W. and MacFarlane, A.E. (2011) 'Public attitudes to the use in research of personal health information from general practitioners' records: a survey of the Irish general public', *Journal of Medical Ethics*, Vol. 37, No. 1, pp.50–55, DOI: 10.1136/jme.2010.037903
- Caligtan, C.A. and Dykes, P.C. (2011) 'Electronic health records and personal health records', *Seminars in Oncology Nursing*, Vol. 27, No. 3, pp.218–228, DOI: 10.1016/j.soncn.2011.04.007
- Clerkin, P., Buckley, B.S., Murphy, A.W. and Macfarlane, A.E. (2013) 'Patients' views about the use of their personal information from general practice medical records in health research: a qualitative study in Ireland', *Family Practice*, Vol. 30, No. 1, pp.105–112.

- Curtis, J., Cheng, S., Rose, K. and Tsai, O. (2011) 'Promoting adoption, usability, and research for personal health records in Canada: the MyChart experience', *Healthcare Management Forum*, Vol. 24, No. 3, pp.149–154.
- Di Stefano, G., Peteraf, M. and Verona, G. (2010) 'Dynamic capabilities deconstructed: a bibliographic investigation into the origins, development, and future directions of the research domain', *Industrial and Corporate Change*, dtq027.
- Do, N.V., Barnhill, R., Heermann-Do, K.A., Salzman, K.L. and Gimbel, R.W. (2011) 'The military health system's personal health record pilot with Microsoft HealthVault and Google Health', *Journal of the American Medical Informatics Association*, Vol. 18, No. 2, pp.118–124.
- Dohan, M.S., Abouzahra, M. and Tan, J. (2014) 'Mobile personal health records: research agenda for applications in global health', *Paper presented at the 47th Hawaii International Conference on System Sciences, HICSS*, Waikoloa, HI.
- Emani, S., Yamin, C.K., Peters, E., Karson, A.S., Lipsitz, S.R., Wald, J.S. and Bates, D.W. (2012) 'Patient perceptions of a personal health record: a test of the diffusion of innovation model', *Journal of Medical Internet Research*, Vol. 14, No. 6, e150.
- eRedbook. (2016) *The Online Version of your Personal Child Health Record* [online] <https://eredbook.org.uk/> (accessed 01/06/2016).
- Fahimnia, B., Sarkis, J. and Davarzani, H. (2015) 'Green supply chain management: a review and bibliometric analysis', *International Journal of Production Economics*, Vol. 162, Part C, pp.101–114.
- Fetter, M.S. (2009a) 'Personal health records', *Issues in Mental Health Nursing*, Vol. 30, No. 10, pp.652–654.
- Fetter, M.S. (2009b) 'Personal health records: protecting behavioral health consumers' rights', *Issues in Mental Health Nursing*, Vol. 30, No. 11, pp.720–722.
- Gaskin, G.L., Longhurst, C.A., Slayton, R. and Das, A.K. (2011) 'Sociotechnical challenges of developing an interoperable personal health record: lessons learned', *Applied Clinical Informatics*, Vol. 2, No. 4, pp.406–419.
- Genitsaridi, I., Kondylakis, H., Koumakis, L., Marias, K. and Tsiknakis, M. (2013) 'Towards intelligent personal health record systems: review, criteria and extensions', paper presented at the *Procedia Computer Science*.
- Genitsaridi, I., Kondylakis, H., Koumakis, L., Marias, K. and Tsiknakis, M. (2015) 'Evaluation of personal health record systems through the lenses of EC research projects', *Computers in Biology and Medicine*, 1 April, Vol. 59, pp.175–185.
- Grant, R.W., Wald, J.S., Schnipper, J.L., Gandhi, T.K., Poon, E.G., Orav, E.J. and Middleton, B. (2008) 'Practice-linked online personal health records for type 2 diabetes mellitus: a randomized controlled trial', *Archives of Internal Medicine*, Vol. 168, No. 16, pp.1776–1782.
- Greenhalgh, T., Hinder, S., Stramer, K., Bratan, T. and Russell, J. (2010) 'Adoption, non-adoption, and abandonment of a personal electronic health record: case study of HealthSpace', *BMJ (Online)*, Vol. 341, No. 7782, p.1091.
- Gu, Y. and Day, K. (2013) 'Propensity of people with long-term conditions to use personal health records', paper presented at the *Studies in Health Technology and Informatics*.
- Haggstrom, D.A., Saleem, J.J., Russ, A.L., Jones, J., Russell, S.A. and Chumbler, N.R. (2011) 'Lessons learned from usability testing of the VA's personal health record', *Journal of the American Medical Informatics Association*, Vol. 18, No. 1, pp.13–17.
- Hampshire, A.J., Blair, M.E., Crown, N.S., Avery, A.J. and Williams, E.I. (2004) 'Variation in how mothers, health visitors and general practitioners use the personal child health record', *Child: Care, Health and Development*, Vol. 30, No. 4, pp.307–316.
- Househ, M.S., Borycki, E.M., Rohrer, W.M. and Kushniruk, A.W. (2014) 'Developing a framework for meaningful use of personal health records (PHRs)', *Health Policy and Technology*, Vol. 3, No. 4, pp.272–280.

- Hudson, D.L. and Cohen, M.E. (2008) 'Temporal trend analysis in personal health records', paper presented at the *Proceedings of the 30th Annual International Conference of the IEEE Engineering in Medicine and Biology Society, EMBS'08 – 'Personalized Healthcare through Technology'*.
- Hudson, D.L. and Cohen, M.E. (2010) 'Uncertainty and complexity in personal health records', *Conference proceedings: ... Annual International Conference of the IEEE Engineering in Medicine and Biology Society. IEEE Engineering in Medicine and Biology Society. Conference*, pp.6773–6776.
- Jarneving, B. (2007) 'Bibliographic coupling and its application to research-front and other core documents', *Journal of Informetrics*, Vol. 1, No. 4, pp.287–307.
- Kaelber, D. and Pan, E.C. (2008) 'The value of personal health record (PHR) systems', *AMIA ... Annual Symposium proceedings/AMIA Symposium*, AMIA Symposium, pp.343–347.
- Kaelber, D.C., Jha, A.K., Johnston, D., Middleton, B. and Bates, D.W. (2008) 'A research agenda for personal health records (PHRs)', *Journal of the American Medical Informatics Association*, Vol. 15, No. 6, pp.729–736.
- Kahn, J.S., Hilton, J.F., Van Nunnery, T., Leasure, S., Bryant, K.M., Hare, C.B. and Thom, D.H. (2010) 'Personal health records in a public hospital: experience at the HIV/AIDS clinic at San Francisco General Hospital', *Journal of the American Medical Informatics Association*, Vol. 17, No. 2, pp.224–228, DOI:10.1136/jamia.2009.000315.
- Kannry, J., Beuria, P., Wang, E. and Nissim, J. (2012) 'Personal health records: meaningful use, but for whom?', *Mount Sinai Journal of Medicine*, Vol. 79, No. 5, pp.593–602.
- Kerns, J.W., Krist, A.H., Longo, D.R., Kuzel, A.J. and Woolf, S.H. (2013) 'How patients want to engage with their personal health record: a qualitative study', *BMJ Open*, Vol. 3, e002931.
- Kessler, M. (1963) 'An experimental study of bibliographic coupling between technical papers (corresp.)', *IEEE Transactions on Information Theory*, Vol. 9, No. 1, pp.49–51, DOI: 10.1109/TIT.1963.1057800.
- Kogut, S.J., Goldstein, E., Charbonneau, C., Jackson, A. and Patry, G. (2014) 'Improving medication management after a hospitalization with pharmacist home visits and electronic personal health records: an observational study', *Drug, Healthcare and Patient Safety*, Vol. 6, pp.1–6.
- Koumaditis, K. (2015) 'Governance of service-oriented architecture in a healthcare organization: a case study', *Journal of Information Technology Case and Application Research*, Vol. 17, No. 3–4, pp.130–155.
- Koumaditis, K., Themistocleous, M. and Rupino Da Cunha, P. (2013) 'SOA implementation critical success factors in healthcare', *Journal of Enterprise Information Management*, Vol. 26, No. 4, pp.343–362.
- Krist, A.H., Peele, E., Woolf, S.H., Rothemich, S.F., Loomis, J.F., Longo, D.R. and Kuzel, A.J. (2011) 'Designing a patient-centered personal health record to promote preventive care', *BMC Medical Informatics and Decision Making*, Vol. 11, No. 1.
- Krist, A.H., Woolf, S.H., Bello, G.A., Sabo, R.T., Longo, D.R., Kashiri, P. and Cohn, J. (2014) 'Engaging primary care patients to use a patient-centered personal health record', *Annals of Family Medicine*, Vol. 12, No. 5, pp.418–426.
- Li, M., Yu, S., Ren, K. and Lou, W. (2010) 'Securing personal health records in cloud computing: patient-centric and fine-grained data access control in multi-owner settings', *LNICST, Lecture Notes of the Institute for Computer Sciences, Social-Informatics and Telecommunications Engineering*, Vol. 50, pp.89–106.
- Li, M., Yu, S., Zheng, Y., Ren, K. and Lou, W. (2013) 'Scalable and secure sharing of personal health records in cloud computing using attribute-based encryption', *IEEE Transactions on Parallel and Distributed Systems*, Vol. 24, No. 1, pp.131–143.
- Liu, L.S., Shih, P.C. and Hayes, G.R. (2011) 'Barriers to the adoption and use of personal health record systems', paper presented at the *ACM International Conference Proceeding Series*.
- Lokman, I.M. (2007) 'The rise and rise of citation analysis', *Physics World*, Vol. 20, No. 1, p.32.

- Lupton, D. (2013) 'Quantifying the body: monitoring and measuring health in the age of mHealth technologies', *Critical Public Health*, Vol. 23, No. 4, pp.393–403.
- Martin, J.C., Avant, R.F., Bowman, M.A., Bucholtz, J.R., Dickinson, J.C., Evans, K.L. and McMillen, M.A. (2004) 'The future of family medicine: a collaborative project of the family medicine community', *Annals of Family Medicine*, Vol. 2, No. 1, pp.S3–S32, DOI: 10.1370/afm.130.
- McInnes, D.K., Solomon, J.L., Bokhour, B.G., Asch, S.M., Ross, D., Nazi, K.M. and Gifford, A.L. (2011) 'Use of electronic personal health record systems to encourage HIV screening: an exploratory study of patient and provider perspectives', *BMC Research Notes*, Vol. 4.
- McInnes, D.K., Solomon, J.L., Shimada, S.L., Petrakis, B.A., Bokhour, B.G., Asch, S.M. and Gifford, A.L. (2013) 'Development and evaluation of an internet and personal health record training program for low-income patients with HIV or Hepatitis C', *Medical Care*, Vol. 51, Nos. 1–3, pp.S62–S66.
- Menon, A.S., Greenwald, S., Ma, T.J., Kooshesh, S. and Duriseti, R. (2012) 'Patient and physician willingness to use personal health records in the emergency department', *Western Journal of Emergency Medicine*, Vol. 13, No. 2, pp.172–175.
- Mora, F. (2012) 'The demise of Google Health and the future of personal health records', *International Journal of Healthcare Technology and Management*, Vol. 13, Nos. 5–6, pp.363–377.
- Nazi, K.M. (2010) 'Veterans' voices: use of the American Customer Satisfaction Index (ACSI) Survey to identify My HealtheVet personal health record users' characteristics, needs, and preferences', *Journal of the American Medical Informatics Association*, Vol. 17, No. 2, pp.203–211.
- Ozok, A.A., Gurses, A.P., Wu, H., Nelson, M., Moen, D. and Wei, J. (2009) 'Usability and user acceptance for personal health records: a perspective from healthcare citizens', *LNCS, Lecture Notes in Computer Science (including subseries Lecture Notes in Artificial Intelligence and Lecture Notes in Bioinformatics)*, Vol. 5621, pp.690–699.
- Pagliari, C., Detmer, D. and Singleton, P. (2007) 'Potential of electronic personal health records', *British Medical Journal*, Vol. 335, No. 7615, pp.330–333.
- Pai, H.H., Lau, F., Barnett, J. and Jones, S. (2013) 'Meeting the health information needs of prostate cancer patients using personal health records', *Current Oncology*, Vol. 20, No. 6, pp.e561–e569.
- Patel, V.N., Dhopeswarkar, R.V., Edwards, A., Barrón, Y., Sparenborg, J. and Kaushal, R. (2012) 'Consumer support for health information exchange and personal health records: a regional health information organization survey', *Journal of Medical Systems*, Vol. 36, No. 3, pp.1043–1052.
- Persson, O., Danell, R. and Schneider, J.W. (2009) 'How to use Bibexcel for various types of bibliometric analysis', *Celebrating Scholarly Communication Studies: A Festschrift for Olle Persson at his 60th Birthday*, pp.9–24.
- Piras, E.M. and Zanutto, A. (2010) 'Prescriptions, X-rays and grocery lists: designing a personal health record to support (the invisible work of) health information management in the household', *Computer Supported Cooperative Work*, Vol. 19, No. 6, pp.585–613.
- Puustjärvi, J. and Puustjärvi, L. (2009) 'Designing and implementing semantic personal health records', paper presented at the *Proceedings of the IADIS International Conference WWW/Internet, ICWI*.
- Puustjärvi, J. and Puustjärvi, L. (2010) 'Automating the importation of medication data into personal health records', paper presented at the *HEALTHINF 2010 – 3rd International Conference on Health Informatics, Proceedings*.
- Ramos-Rodríguez, A.R. and Ruíz-Navarro, J. (2004) 'Changes in the intellectual structure of strategic management research: a bibliometric study of the Strategic Management Journal, 1980–2000', *Strategic Management Journal*, Vol. 25, No. 10, pp.981–1004.

- Reeve, J., Hosking, R. and Allinson, Y. (2013) 'Personal electronic health records: the start of a journey', *Australian Prescriber*, Vol. 36, No. 3, pp.70–73.
- Reti, S.R., Feldman, H.J., Ross, S.E. and Safran, C. (2010) 'Improving personal health records for patient-centered care', *Journal of the American Medical Informatics Association*, Vol. 17, No. 2, pp.192–195.
- Roblin, D.W., Houston II, T.K., Allison, J.J., Joski, P.J. and Becker, E.R. (2009) 'Disparities in use of a personal health record in a managed care organization', *Journal of the American Medical Informatics Association*, Vol. 16, No. 5, pp.683–689, DOI: 10.1197/jamia.M3169.
- Seldon, H.L. (2014) 'Personal health records in southeast Asia part 1 – a way to computerize healthcare?', *Electronic Journal of Health Informatics*, Vol. 8, No. 1.
- Seldon, H.L., Moghaddasi, H., Seo, W.J. and JoNah, S.W. (2014) 'Personal health records in SE Asia part 2: a digital portable health record', *Electronic Journal of Health Informatics*, Vol. 8, No. 1.
- Sharpe, D. (1997) 'Of apples and oranges, file drawers and garbage: why validity issues in meta-analysis will not go away', *Clinical Psychology Review*, Vol. 17, No. 8, pp.881–901.
- Somner, J.E., Sii, F., Bourne, R., Cross, V. and Shah, P. (2013) 'What do patients with glaucoma think about personal health records?', *Ophthalmic and Physiological Optics*, Vol. 33, No. 6, pp.627–633.
- Sue, V.M., Griffin, M.T. and Allen, J.Y. (2013) 'Beyond adoption: individual differences in the use of personal health record features in an integrated healthcare organization', *International Journal of Biomedical Engineering and Technology*, Vol. 11, No. 3, pp.252–269.
- Tang, P.C., Ash, J.S., Bates, D.W., Overhage, J.M. and Sands, D.Z. (2006) 'Personal health records: definitions, benefits, and strategies for overcoming barriers to adoption', *Journal of the American Medical Informatics Association: JAMIA*, Vol. 13, No. 2, pp.121–126, DOI: 10.1197/jamia.M2025.
- Thygesen, S.K., Christiansen, C.F., Christensen, S., Lash, T.L. and Sørensen, H.T. (2011) 'The predictive value of ICD-10 diagnostic coding used to assess Charlson comorbidity index conditions in the population-based Danish National Registry of Patients', *BMC Medical Research Methodology*, Vol. 11, No. 83.
- Tom, J.O., Mangione-Smith, R., Solomon, C. and Grossman, D.C. (2012) 'Integrated personal health record use: association with parent-reported care experiences', *Pediatrics*, Vol. 130, No. 1, pp.e183–e190.
- Toscos, T., Daley, C., Heral, L., Doshi, R., Chen, Y.C., Eckert, G.J. and Mirro, M.J. (2016) 'Impact of electronic personal health record use on engagement and intermediate health outcomes among cardiac patients: a quasi-experimental study', *Journal of the American Medical Informatics Association*, Vol. 23, No. 1, pp.119–128.
- Tsai, J. and Rosenheck, R.A. (2012) 'Use of the internet and an online personal health record system by US veterans: comparison of Veterans Affairs mental health service users and other veterans nationally', *Journal of the American Medical Informatics Association*, Vol. 19, No. 6, pp.1089–1094.
- Van Eck, N.J. and Waltman, L. (2014) 'Visualizing bibliometric networks', *Measuring Scholarly Impact*, Springer, pp.285–320.
- Vogel, R. and Güttel, W.H. (2013) 'The dynamic capability view in strategic management: a bibliometric review', *International Journal of Management Reviews*, Vol. 15, No. 4, pp.426–446.
- Wagner, P.J., Dias, J., Howard, S., Kintziger, K.W., Hudson, M.F., Seol, Y.H. and Sodomka, P. (2012) 'Personal health records and hypertension control: a randomized trial', *Journal of the American Medical Informatics Association*, Vol. 19, No. 4, pp.626–634.
- Waltman, L., van Eck, N.J. and Noyons, E.C.M. (2010) 'A unified approach to mapping and clustering of bibliometric networks', *Journal of Informetrics*, Vol. 4, No. 4, pp.629–635.

- Walton, S. and Bedford, H. (2007) 'Parents' use and views of the national standard personal child health record: a survey in two primary care trusts', *Child: Care, Health and Development*, Vol. 33, No. 6, pp.744–748.
- Wang, C., Liu, X. and Li, W. (2012) 'Implementing a personal health record cloud platform using ciphertext-policy attribute-based encryption', paper presented at the *Proceedings of the 2012 4th International Conference on Intelligent Networking and Collaborative Systems, INCoS*.
- Wang, C., Liu, X. and Li, W. (2013) 'Design and implementation of a secure cloud-based personal health record system using ciphertext-policy attribute-based encryption', *International Journal of Intelligent Information and Database Systems*, Vol. 7, No. 5, pp.389–399.
- Weitzman, E.R., Kaci, L. and Mandl, K.D. (2010) 'Sharing medical data for health research: the early personal health record experience', *Journal of Medical Internet Research*, Vol. 12, No. 2.
- Weitzman, R.E., Kaci, L. and Mandl, D.K. (2010) 'Sharing medical data for health research: the early personal health record experience', *Journal of Medical Internet Research*, Vol. 12, No. 2, p.e14.
- Wright, C.M. and Reynolds, L. (2006) 'How widely are personal child health records used and are they effective health education tools? A comparison of two records', *Child: Care, Health and Development*, Vol. 32, No. 1, pp.55–61.
- Wynia, M. and Dunn, K. (2010) 'Dreams and nightmares: practical and ethical issues for patients and physicians using personal health records', *Journal of Law, Medicine and Ethics*, Vol. 38, No. 1, pp.64–73.
- Yamin, C.K., Emani, S., Williams, D.H., Lipsitz, S.R., Karson, A.S., Wald, J.S. and Bates, D.W. (2011) 'The digital divide in adoption and use of a personal health record', *Archives of Internal Medicine*, Vol. 171, No. 6, pp.568–574, DOI: 10.1001/archinternmed.2011.34.
- Yau, G.L., Williams, A.S. and Brown, J.B. (2011) 'Family physicians' perspectives on personal health records: qualitative study', *Canadian Family Physician*, Vol. 57, No. 5, pp.e178–e184.
- Zupic, I. and Čater, T. (2015) 'Bibliometric methods in management and organization', *Organizational Research Methods*, Vol. 18, No. 3, pp.429–472.