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Categorising the Personal Health Record–A Systematic Review and Analysis of the Term’s Use in the Literature

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Abstract: The purposes of this article are to investigate how the term 'personal health record' (PHR) is used in the literature and to offer a proposal for future uses of the term. A systematic literature review was conducted to identify and analyse the use of PHR definitions. Four databases were reviewed: ScienceDirect, IEEE Xplore, ProQuest and PubMed. We found and screened a total of 1,781 articles published between 2000 and 2017, only 233 (19%) of which defined PHR. These definitions often conflicted with or even contradicted one another. Even the most commonly used definitions did not properly define PHR, focusing instead on specific attributes and functionalities of PHRs or setting questionable limitations on what should be seen as a PHR. Thus, a clear and systematic categorisation for defining PHRs is needed, and one is offered in this article. This kind of hierarchical definition allows for flexible use of the term. When a term is defined with different levels of abstraction, it offers a flexible focus for other purposes while still fulfilling the need for a clear definition.

Keywords: PHR; personal health record; review; definition; terminology; hierarchy; categorisation; taxonomy.

1 Introduction

The term 'personal health record' (PHR) has been a key term in eHealth research over the last decade due to the interest in developing consumer- and citizen-centric healthcare systems (Demiris 2012, Kim et al. 2011, Lahtiranta 2009). The term was coined in the late 1970s (Kim et al. 2011, Heart et al. 2017) and is now commonly used in the literature. However, PHR does not yet have a generally accepted definition, as has been repeatedly noted (Tang et al. 2006, Kaelber et al. 2008, Reti et al. 2009, Jian et al. 2012, Pincioli & Pagliari 2015, Urbauer et al. 2015, Thompson et al. 2016, Rantanen & Koskinen 2018). Likewise, research findings indicate that over half of interviewed health professionals were not familiar with the term (Huba & Zhang 2012). Policy-makers, academics, healthcare providers, technology firms and other health stakeholders have been debating, trying to define and promoting the use and development of PHRs for more than a decade (Davidson et al. 2015). Despite these efforts, we have not achieved a commonly accepted and widely used definition of PHR, so that remains a challenge that must be met (see e.g. Tang et al. 2006, National Alliance for Health Information Technology 2008).

The inconsistent use of PHR in the academic literature poses several problems. First, achieving a fully satisfactory body of knowledge will be more challenging or even impossible without sufficient consensus. For instance, reviews considering the advantages of PHRs are difficult to compare if one article is about patient-controlled files stored on a USB drive and the other is about a patient portal extension of the healthcare information system operated by a hospital. Second, only one fifth of papers reviewed offered any definition at all, thus expanding the possibilities of different and even contradictory interpretations. Third, a rational public discourse (see Habermas 1996, 2018) about PHRs is not possible without a common ground, at least among researchers in the field and healthcare professionals. If large numbers of professionals are not familiar with the term, it is reasonable to believe that potential users, policy-makers and other key stakeholders will also not be able to adequately define PHRs. Fourth, clinical practices need to examine the potential of different kinds of PHRs from professionals' perspectives. Overall, the inconsistent use of the term may create barriers to finding evidence for what PHRs can offer in different contexts.

The literature reveals three main types of PHR: stand-alone, tethered and interconnected (or integrated) (Tang et al. 2006, Archer et al. 2011). The most independent is the stand-alone PHR, which is not connected to other systems – such as electronic medical records (EMRs) or electronic health records (EHRs) – and thus can be and usually is personally maintained (Tang et al. 2006). The second type is the tethered PHR, which is either an integral part of or at least dependent on a host system; examples are EHRs or EMRs provided by healthcare or other organisations (Tang et al. 2006, Nazi et al. 2010, Archer et al. 2011, Gaskin et al. 2011). The third type, the interconnected PHR, describes systems connected to more than one other system and has been called the most sophisticated, comprehensive and valuable form (Tang et al. 2006, Davis, Roudsari, Raworth, Courtney & MacKay 2017). Without ignoring other nuanced differences among PHRs, these three types represent the main approaches to and viewpoints on PHR development, which has led to a variety of PHR products that differ substantially from one another (Tang et al. 2006, Genitsaridi et al. 2015).

Given that PHRs have been such a frequent topic in eHealth and medical informatics, it is not surprising that several reviews have shed light on previous PHR research. Kim et al. (2011) focused on the history of PHRs, Ennis et al. (2014) on stakeholder involvement in PHR development, Bouayad et al. (2017) on PHR data types and functionalities and Roehrs et al. (2017) on taxonomy and identifying challenges and open questions in the literature.

Thus, despite the vast interest in the topic and the volume of literature dedicated to studying it, a central problem remains: we do not have a precise understanding of what a PHR actually is. This problem leads to many other issues through misunderstandings and misinterpretations. Not having a shared understanding of what we mean by PHR weakens all discussions about it; for instance, it becomes difficult to compare the results of previous research (Rantanen & Koskinen 2018). What is missing is a review of the definitions of PHR used in the literature.

To fill this gap, we conducted a systematic literature review of the definitions of PHR used in scientific articles. In the next section, we describe our research methodology, research questions and data processing approach. In Section Three, we present the results of the systematic literature review. In Section Four, we suggest a hierarchical definition for PHR, which offers a solution to the problem of creating a generic PHR definition that still contains enough detail about the various types of PHRs. In Section Five, we present the implications of the results and acknowledge the limitations of this review. Finally, we summarize the paper.

2 Research Methodology

2.1 Study design

A pre-study was conducted to obtain an overview of the situation (see Rantanen & Koskinen 2018), based on which the need for a systematic literature review of definitions of the term 'personal health record' was noted. From the pre-study findings, we developed the following research questions:

RQ1: What kinds of definitions of PHRs are used in the medical informatics scientific literature?

RQ2: What kind of systematic hierarchy for the term PHR could facilitate a coherent use of the term in the future?

To answer these questions, we conducted a search of relevant fields in medical informatics to create a systematic literature review. Our review is based on Webster and Watson's process Webster & Watson (2002), adjusted by recommendations proposed by Rowe Rowe (2014). We chose four databases: ProQuest, ScienceDirect, PubMed and IEEE Xplore. ProQuest and ScienceDirect are multidisciplinary databases that index most articles about medical informatics from different perspectives. PubMed was included since it contains articles from a biomedical perspective, while IEEE Xplore was chosen for its more technical focus. Thus, these databases cover most technical, medical and multidisciplinary literature that focuses on medical informatics. The popularity of PHRs as a research topic required us to add certain other limitations to our review. We narrowed our search to the 2000–2017 time span, as we wanted to focus on the use of the term rather than its history and early evolution, which has been already studied (see Kim et al. 2011).

We tested several search strings on these databases but decided to use the simple 'personal health record' to narrow the number of results and avoid false positives. We also designed selection criteria that aimed to exclude articles that were not from scientific journals, were not written in English or only mentioned 'personal health record' in the references. The design of the entire study is represented in Figure 1. The following subsection describes this research in greater detail.

2.2 Data collection

We conducted a systematic literature review (see flow diagram of the review process in Figure 1 of four databases (IEEE Xplore, ProQuest, PubMed and ScienceDirect). In phase one, articles from 2000 to 2017 were searched in two parts: articles from 2000 to 2016 were searched on 24 October 2017 and articles from 2017 on 8 February 2018.

The searches were carried out using the search query 'personal health record' in journal papers in all four databases. We chose not to include any other terms in the search query and decided to focus on the use of the term itself rather than any subject area that used it. We wanted to concentrate on the term because of the variations in its meanings and interpretations (see Kim et al. 2011, Arens-Volland et al. 2015). We also want to underline that we did not evaluate the articles based on content or scholarly value, but only on how the term 'personal health record' was defined and used.

In the ProQuest database, we used additional filters limiting our search to only peer-reviewed journal articles written in English that were available in full text. We limited the PubMed search to papers available in full text and written in English. The four databases provided 1,781 papers for the second phase of our review process.

In phase two, we went through the papers and removed duplicates, conference proceedings, non-scientific articles, those that did not contain the term 'personal health record', those that used the term only in reference lists and those not written in English; a total of 547 articles were removed in this phase, leaving 1,234 articles for final review. In phase three, all selected papers were reviewed, analysed and categorised. This is described in more detail in the next subsection. The various phases and numbers of articles remaining at each step are presented in Figure 1.

2.3 Data categorisation and analysis

In phase three, we systematically examined the articles and divided them into two categories: those that did not have any definitions of PRH ($n=1,001$) and those that did ($n=233$). In the papers without any definition of the term, the term is used without explanation. By 'definition', we mean that the use of the term is either described in the article itself or in another article(s) that defines it and is cited in the original article. The next step was to categorise those articles that did provide some definition into more clear subcategories to help illustrate how the term was defined. We found three subcategories: *i*) articles whose authors' provided their own developed definitions for the term, *ii*) articles that referred to some other definition(s) in their own definition, and *iii*) articles that directly cited other definitions without providing a definition.

After categorising definitions of the term into subcategories, articles with a definition were screened again by both authors to ensure that they agreed on the article's inclusion in a given subcategory (*i/ii/iii*) (Note: The assignment of definitions to subcategories involved a fine line drawn by the authors; hence, others could come up with a somewhat different

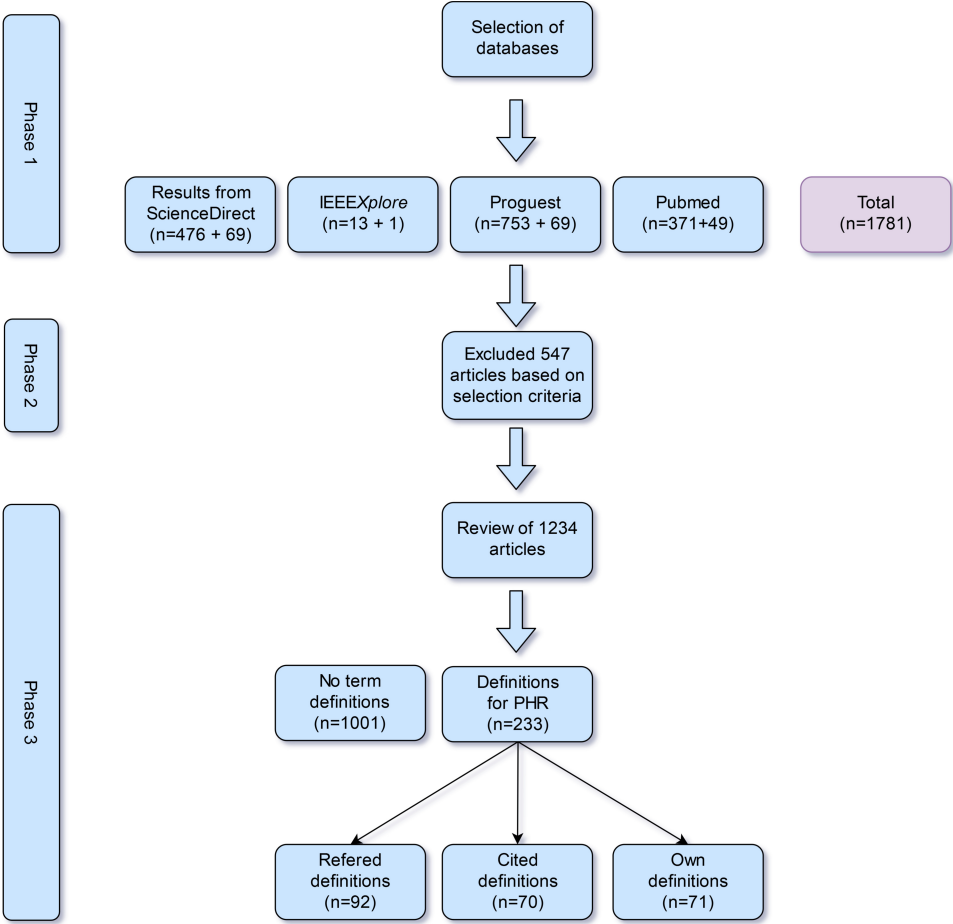


Figure 1 Review process

outcome. However, most articles fit quite well into a specific category, so the outcome should be largely the same if the process were carried out by other researchers).

Papers including references were subjected to further analysis. To answer RQ1 (What kinds of definitions of PHRs are used in the medical informatics scientific literature?), all articles (223) with a definition of PHR were surveyed and coded. This was done by one author, but after the first round both authors approved the selections. For coding, the NVivo Pro 11 software package was used. Microsoft Excel was used for analysing and categorising articles into three groups: 1) articles with definitions based on references, 2) articles that used their own definition without citations and 3) and direct citations of other definitions. The 10 most frequently cited definitions were further analysed to see the kinds of definitions that have been most heavily used in the literature.

3 Results

3.1 Overview of articles with a definition

A total of 1,234 unique articles were reviewed, with only 233 (19%) including definitions. This means that a large majority (81%) of articles using the term 'personal health record' did so without defining it. In this review, we found several definitions of the term. Definitions provided by article author(s) were used in 71 (31%) cases, while 92 (40%) definitions were based on one or more references, and 70 (30%) papers directly cited sources with definitions.

Definitions based on references include articles that defined PHRs using other articles as references or citing them directly. Some authors also created their own definitions based on sources; these were counted as referred or cited definitions.

3.2 Own definitions

The author definitions used in 71 papers (31% of all definitions) fall into three broad types (see Table 1.)

First, there are definitions with a high level of abstraction that describe only aspects of personal control of information that is related to 'health'. Thus, these definitions employ as a higher level of abstraction of a PHR, focusing only on its being a compilation of health-related information that an individual controls and manages. These definitions do not consider PHR technology or specific attributes of PHRs, but merely the concept of PHRs.

The second type of definition includes notions about more specific technologies or properties of PHRs. These definitions contain detailed statements of the technical type of PHR. For instance, they specify some type of technology or properties of a PHR (electronic, online, etc.). Thus, these definitions differ from the first type of definitions by being more precise.

The third category of definition comprises those that do not fit in either of the first two categories. They are either very broad, very detailed, unclear or focus on specific PHR solutions. As these definitions are more case-specific, it is not reasonable to separate them further into specific types of definitions.

3.3 Analysis of the 10 most frequently used definitions

In the further analysis of papers using references to define PHRs (n=162), 126 references were used a total of 280 times. In 85 articles, PHR definitions were cited only once,

Table 1 Types of own definitions

Type of definition	References
High abstraction level	(Sittig 2002, van Deursen et al. 2008, Council on Clinical Information Technology 2009, Ahsan et al. 2012, Nokes et al. 2012, Simon & Seldon 2012, Adler-Milstein et al. 2014, Hamdi et al. 2014, Laxman et al. 2015, Robotham et al. 2015, Xavier & Chandrasekar 2015)
Defines specific technology or properties	(Stead et al. 2005, Bria 2006, Safran et al. 2007, Buettner & Fadem 2008, Atreja et al. 2008, Fuji & Galt 2008, Grossman et al. 2009, Kabachinski 2009, Jones et al. 2010, Plovnick 2010, Melton 2010, Daniel et al. 2011, Gaskin et al. 2011, Lafky & Horan 2011, Springman 2011, Kierkegaard 2012, Fernández-alemán et al. 2013, Musso et al. 2013, Li et al. 2013, Navaneethan et al. 2013, Sivakumar & Geetha 2014, Sunyaev 2014, Knapfel et al. 2014, Qian et al. 2015, Ro et al. 2015, Comandé et al. 2015, Yang et al. 2015, Harper 2016, Groenen et al. 2016, King et al. 2016, Bruns et al. 2016, Walsh et al. 2017, Roehrs et al. 2017, Shah & Liebovitz 2017)
Other (Not fitting in categories above)	(Weitz et al. 2003, Hegyvary 2004, Gold & Ball 2007, Loeppke 2008, Reti et al. 2009, Frost & Massagli 2009, Pirtle & Chandra 2011, Chung et al. 2011, Emani et al. 2012, Kensing 2012, Jian et al. 2012, Otsuka et al. 2013, Olaronke et al. 2014, Danwei et al. 2014, Kyazze et al. 2014, Bajwa 2014, Urbauer et al. 2015, Crouch et al. 2015, Carter et al. 2015, Triantafyllopoulos et al. 2016, Woolfenden et al. 2016, van Vugt et al. 2016, Haynes 2017, Davis, Roudsari & Courtney 2017, Kao & Liebovitz 2017)

comprising almost one third of the references used (30%), while 19 articles were referred to twice (n=38, 14% of all citations) and nine were referred to three times (n=27, 9% of all citations). The remaining 14 references were used in four or more articles a total of 139 times (31%).

Although the figures reported above show that the references used in defining PHRs are rather scattered, a few were used in definitions more often than others (see Table 2). Another interesting note about all the references is that although more references came from scientific articles (n=77; 61% of all references) than institutional reports and online sources (n=49; 39% of all references), the latter were used more often on a per-reference basis. While scientific articles were used as references a total of 156 times (56%), institutional reports and online sources were used 124 times (44%).

To better understand the impact of the references most frequently used to define PHRs, we analyse the 10 most cited definitions more closely in the following subsections. The aim is to identify possible similarities or disparities between definitions. Likewise, we view the context and source of each definition to understand the possible worldview and premises that may have affected the final shaping of the definition; for example, whether it is based on individuals' academic research or work by institutional bodies. It is noteworthy that most reports used as references originated from institutions or professional associations based in the United States, such as the Markle Foundation, the American Health Information Management Association (AHIMA) and the National Alliance for Health Information Technology (NAHIT). Thus, these bodies appear to have a significant impact on the terminology used in the medical informatics field.

3.3.1 *Definition used by Tang et al.(2006)*

The article with the most frequent references was Tang et al. (2006), with 35. However, we want to emphasise that those 35 articles used this article as a citation in their definitions. Thus, the overall citation numbers differ. For instance, Tang et al. (2006) has been cited 908 times (Scopus, accessed 7 January 2020), which shows the importance of this article.

Another significant issue about Tang et al. (2006) is that, even though it is important and widely used, it is not the original source for the definition it uses. Rather, Tang et al. use the definition introduced by the Markle Foundation: "*An electronic application through which individuals can access, manage and share their health information, and that of others for whom they are authorised, in a private, secure, and confidential environment.*" in their final report, *Connecting for Health* (Markle Foundation 2003) (see Tang et al. 2006, p. 122).

However, Tang et al. (2006) state that the Markle Foundation definition is incomplete and needs clarification to help understand how PHRs could be used. They also point out the differences between EHRs and PHRs and that there are different kinds of PHRs with diverse technical and logical foundations. Overall, their article offers a good view of the different kinds of PHRs and the challenges they pose and possibilities they offer for individuals and the healthcare sector, especially when the article was published. This clear grasp of the complexity of PHRs may be why Tang et al. (2006) do not offer their own clearly stated definition of PHR; they focus on portraying what PHR is about instead of committing to an overly narrow definition.

3.3.2 *Markle Foundation definition (2003)*

The Markle Foundation's definition (Markle Foundation 2003) was the second most frequently used; 33 papers refer to it directly. As mentioned above, Tang et al. (2006) do not

Table 2 10 most frequently used references in the articles

	Reference used	Times used	In articles
1	Tang et al. (2006). Personal Health Records: Definitions, Benefits, and Strategies for Overcoming Barriers to Adoption. Tang et al. (2006)	35	(Lee et al. 2007, Kim et al. 2009, Bates & Bitton 2010, Mitchell & Begoray 2010, Nazi et al. 2010, Wijler et al. 2010, Steward et al. 2010, Sujansky et al. 2010, Pearson et al. 2011, Eccher et al. 2011, Wibe et al. 2011, Sourla et al. 2012, Ahmadi et al. 2012, Carrion Señor et al. 2012, Hilton et al. 2012, Bélanger et al. 2012, Gu et al. 2013, Chen et al. 2013, Gu & Day 2013, Lau et al. 2013, Nazi 2013, Taha et al. 2013, Househ et al. 2014, Czaja 2015, Cabitza et al. 2015, Fujii et al. 2015, Gartrell, Storr, Trinkoff, Wilson & Gurses 2015, Genitsaridi et al. 2015, Chen-Chung et al. 2016, Lester et al. 2016, Alsaah & Saddik 2016, Laranjo et al. 2017, Lee et al. 2017, Roehrs et al. 2017, Zhou et al. 2017)
2	Markle Foundation. (2003). Personal Health Working Group – Final Report. Markle Foundation (2003)	33	(Tang et al. 2006, Staroselsky et al. 2006, Ball et al. 2008, Kaelber et al. 2008, McDaniel et al. 2008, Roblin et al. 2009, Britto et al. 2009, Nazi 2010, Witry et al. 2010, Bonacina et al. 2010, Chumbler et al. 2011, Haggstrom et al. 2011, Hogan et al. 2011, Yamin et al. 2011, Patel et al. 2012, Chen et al. 2012, Calvillo et al. 2013, Cocosila & Archer 2014, Chrischilles et al. 2014, Sieverink et al. 2014, Wiesner & Pfeifer 2014, Ozok et al. 2014, Vydra et al. 2015, Czaja et al. 2015, Demiris 2016, Kneale et al. 2016, Thompson et al. 2016, Toscos et al. 2016, Marsan et al. 2017, Smith et al. 2017, Assadi & Hassanein 2017, Kneale & Demiris 2017, Davis, Roudsari, Raworth, Courtney & MacKay 2017)
3	AHIMA. (2005). e-HIM Personal Health Record Work Group. Defining the Personal Health Record. AHIMA e-HIM Personal Health Record Work Group (2005)	9	(Lee et al. 2007, Fujii et al. 2008, Nazi et al. 2010, Wagner et al. 2010, Ahmadi et al. 2012, Noblin et al. 2012, 2014, Chen et al. 2016, Hsieh et al. 2017)
4	Archer et al. (2011). Personal Health Records: A Scoping Review. Archer et al. (2011)	7	(Nazi 2013, Price, Bellwood & Davies 2015, Price, Bellwood, Kitson, Davies, Weber & Lau 2015, Davidson et al. 2015, Ruiz et al. 2016, Sharit et al. 2016, Davis, Roudsari, Raworth, Courtney & MacKay 2017)
5	Kahn, Aulak and Bosworth. (2009). What It Takes: Characteristics Of The Ideal Personal Health Record. Kahn et al. (2009)	7	(Bonney 2011, Demiris & Thompson 2011, Demiris 2012, Hilton et al. 2012, Chen et al. 2013, Fernandez et al. 2017, Heart et al. 2017)
6	National Alliance for Health Information Technology. (2008). Defining Key Health Information Technology Terms. National Alliance for Health Information Technology (2008)	6	(Thede 2009, Kahn et al. 2009, Demiris & Thompson 2011, Demiris 2012, Chrischilles et al. 2014, Gartrell, Trinkoff, Storr, Wilson & Gurses 2015)
7	Sittig. (2002). Personal Health Records on the Internet: A Snapshot of the Pioneers at the End of the 20th Century. Sittig (2002)	6	(Flores & Dodier 2005, Mikyoung Lee 2006, Lee et al. 2007, Wijler et al. 2010, Hoerbst et al. 2010, Ahmadi et al. 2012)
8	Jones et al. (2010). Characteristics of Personal Health Records: Findings of the Medical Library Association/National Library of Medicine Joint Electronic Personal Health Record Task Force. Jones et al. (2010)	5	(Karamanlis et al. 2012, Monkman & Kushmiruk 2013, Cruz Zapata et al. 2014, Cochran et al. 2015, Shahrabani & Mizrachi 2016)
9	National Committee on Vital and Health Statistics. (2006). Personal Health Records and Personal Health Record Systems – A Report and Recommendations. National Committee on Vital and Health Statistics (2006)	5	(Lee et al. 2007, Pagliari et al. 2007, Nazi 2013, Shimada et al. 2014, Genitsaridi et al. 2015)
10	Pagliari et al. (2007). Potential of Electronic Personal Health Records. Pagliari et al. (2007)	5	(Mitchell & Begoray 2010, Tenforde et al. 2012, Chen et al. 2013, Barbarito et al. 2015, Iljaž et al. 2017)

present their own definition, referring instead to the Markle Foundation definition (Markle Foundation 2003) before considering the characteristics of PHR in the broader sense.

Consequently, the Markle Foundation definition can be regarded as the most widely used definition, as some other commonly cited references use it instead of providing their own. For example, Tang et al. (2006) is used as a reference 35 times in defining PHR, all of which could be counted as second-hand references to the Markle Foundation definition (Markle Foundation 2003). Similarly, the articles by Britto et al. (2009), Tenforde et al. (2011) and Studeny & Coustasse (2014) all refer to the Markle Foundation definition, which is thus the source of 70 definition references, or one quarter (25%) of all 280 references we found in our review.

The Markle Foundation defines PHR as "*an Internet-based set of tools that allows people to access and coordinate their lifelong health information and make appropriate parts of it available to those who need it*" (Markle Foundation 2003, p.3). The notion of PHR as a lifelong repository of health information is absent from the definition as presented by Tang et al. (2006), although it is repeatedly highlighted in the report (Markle Foundation 2003). The exclusion of the time span of the information from the definition is, however, a wise decision since one PHR or even multiple PHRs rarely cover an entire lifetime. Thus, a lifetime cannot plausibly be described as a defining feature of a PHR. Similarly though, one could argue that the notion of "a private, secure, and confidential environment" should not be a part of the definition. For instance, if an electronic PHR is hacked, it is no longer secure, but it does not cease to be a PHR. These characteristics are thus desirable but do not define PHRs.

Seven different Markle Foundation documents were used 43 times as references when defining PHR in the reviewed articles (see Markle Foundation 2003, 2004*b,a*, 2006*a,b*, 2008, 2011); however, most of these documents do not actually contain a definition of a PHR (see Markle Foundation 2004*a*, 2006*b*, 2008, 2011). Similarly, general notions of the Markle Foundation definition without a specific reference were found in an article written by Pottas & Mostert-Phipps (2013). Thus, it seems that authors referring to these sources were relying on the implicit idea of PHR drawn from them or ultimately aimed at the Markle Foundation definition in *Connecting for Health* (Markle Foundation 2003).

3.3.3 Definition by AHIMA (2005)

The AHIMA definition of PHR (AHIMA e-HIM Personal Health Record Work Group 2005) is as follows: "*The personal health record (PHR) is an electronic, lifelong resource of health information needed by individuals to make health decisions. Individuals own and manage the information in the PHR, which comes from healthcare providers and the individual. The PHR is maintained in a secure and private environment, with the individual determining rights of access. The PHR does not replace the legal record of any provider.*"

This definition has problems like those in the Markle Foundation version. It is so narrow that it excludes some solutions that can be regarded as fundamental to PHRs. The first sentence is already problematic in its demand that PHR be electronic and lifelong. Where does this leave paper-based notebooks containing self-collected and self-managed health information? Another interesting question is how a system can be lifelong, given the pace at which technology evolves. The second sentence is also challenging, as it demands that the information must come from the patient or a healthcare provider. What then is the role of other sources, such as wearable sensors that provide different kinds of information that is relevant for individuals' health (see Zhou et al. 2019)? We agree that the demands for

security, privacy and that the PHR not replace legal records are reasonable to ensure the reliability of any PHR system. Still, they do not define what a PHR is and thus should not be included in a definition.

In addition to the definition above, the AHIMA (AHIMA e-HIM Personal Health Record Work Group 2005) article offers a list of PHR attributes in the context of issues of functionality: format, content, privacy, access, control, maintenance, security and interoperability. The article also outlines common data elements that should be present to ensure that consumers are able to use PHRs in different care settings and with multiple care providers.

The AHIMA article is heavily oriented towards the United States, which is understandable because the AHIMA is an American organisation. For example, when describing common data elements, it uses units commonly employed in that country instead of SI units. It also uses the term 'customer', which reflects the private nature of much of the U.S. healthcare system. Overall, this definition and further descriptions of attributes and data types are problematic for global use, even it has value in a U.S. context.

3.3.4 *The definition of PHR used by Archer et al. (2011)*

Archer et al. (2011) state the following about their definition: *We use the term PHR to refer to the records themselves and to the information systems used to support them. Electronic versions can include internet-based portals or computer-based applications. PHRs can be 'tethered', where subsets of information are provided by organisations that maintain patient data electronically, such as physician EMRs, health plan providers, hospitals, or employers. Untethered PHRs can be installed on isolated personal computers or internet-based portal services where only the user enters and maintains personal health data. Paper-based PHRs may also be used by patients to monitor their illnesses, and these can be carried physically by patients to doctor appointments, for example.*

The strength of this definition is that its two levels make it flexible. At the first level, it defines the PHR as both information and the system that contains that information, which allows for different kinds of PHRs to remain within the definition. At the same time, the second level classifies PHRs into three distinct groups: 1) tethered systems provided by an organisation that hosts patient information, 2) untethered systems in which individuals control their own information with an independent solution and 3) paper-based PHRs maintained by individuals.

The remainder of this article focuses on reviewing the PHR literature. The strength of the article by Archer et al. (2011) is that it clearly defines, in the introduction, what is meant by PHR. Thus, it offers a clear and plausible definition for PHR, which is not the case in most of the articles included in our review.

3.3.5 *The definition of PHR used by Kahn et al.(2009)*

Kahn et al. (2009) use the following definition of PHR: *a PHR is an individual's electronic record of health-related information that conforms to nationally recognised interoperability standards, and that can be drawn from multiple sources while being managed, shared and controlled by the individual.* However, this definition is not their own; it was used by NAHIT in a report to the National Coordinator for Health Information Technology (National Alliance for Health Information Technology 2008).

This definition has similar problematic elements as the AHIMA approach(see AHIMA e-HIM Personal Health Record Work Group 2005). The problematic premise is that the

PHR is electronic and 'conforms to nationally recognised interoperability standards', thus excluding paper-based solutions and those that are not explicitly designed for the distinctive traits of the U.S. healthcare system. However, this approach does recognise the spectrum of different kinds of PHR solutions and contexts.

The article itself focuses on defining the characteristics of the ideal PHR and the challenges that create barriers for the broader implementation of PHRs. From a global perspective, the excessively narrow focus on the United States is problematic, as healthcare systems vary widely between countries. Even if one grants that the definition should be limited to the U.S. context, the difference between private and public healthcare in that country already creates two widely different landscapes for PHRs and their realisation.

3.3.6 *The definition of PHR by the NAHIT (2008)*

As noted, the definition that Kahn, Aulak and Bosworth (Kahn et al. 2009) use comes from the NAHIT (National Alliance for Health Information Technology 2008). Thus, it is actually the second most frequently used definition in our review with 13 (six and seven) citations (see Table 2).

The rationale behind the NAHIT report was to create a consensus in the use of different terms *to eliminate confusion around the terms and to provide health care stakeholders with a common understanding of the important components of the health IT infrastructure*. The report also notes that the definitions presented do not solve everything. However, they are an important foundation for addressing important health information technology adoption issues (see National Alliance for Health Information Technology 2008, pp.4-5).

The motivation of the report is visible in its definitions. It focuses on improving U.S. healthcare by providing knowledge of how to increase health information sharing between stakeholders. Information sharing needs a health infrastructure that has systems with standard building blocks (National Alliance for Health Information Technology 2008). From this perspective, the definition presented above is understandable as it aims to increase cooperation between different actors. However, that does not make it viable as a more general term, because it does not seek to describe PHRs at the general level; this makes its use as a definition of PHR in many academic articles problematic.

3.3.7 *The definition of the PHR by Sittig (2002)*

Sittig (2002, p.2) defines PHR as follows: *internet-based personal health records (PHRs) include any internet-accessible application that enables a patient (or guardian, the 'mom') to create, review, annotate or maintain a record of any aspect(s) of their health condition, medication, medical problems, allergies, vaccination history, visit history or communications with their healthcare providers*. Sittig states that this definition is intended to be very broad so as to cover different kinds of internet-based solutions. The article limits PHRs to the internet, as Sittig was providing snapshots of issues and concepts related to online PHR solutions, which were viewed as having the potential to change practices regarding capturing, sorting and transferring health-related information when the article was written. Likewise, the information was of the sort normally collected in healthcare. The article did not focus, for example, on activity information, such as what would be generated by self-tracking device applications, that is relevant to health and is more commonly collected today.

Sittig's decision to exclude PHRs that are not internet-based was perfectly justifiable for the purposes of his article. Nevertheless, it also means that his definition does not recognise stand-alone versions of PHRs and is thus not suitable as a common definition for PHRs.

3.3.8 *The PHR definition by Jones et al. (2010)*

The article aims to examine the state (in 2010) of PHRs as assessed by a task force commissioned by The Medical Library Association and The National Library of Medicine, both U.S. organisations. For this purpose, they first offered the following definition: *Electronic personal health record (PHR): a private, secure application through which an individual may access, manage, and share his or her health information. The PHR can include information that is entered by the consumer and/or data from other sources such as pharmacies, labs, and health care providers. The PHR may or may not include information from the electronic health record (EHR) that is maintained by the health care provider and is not synonymous with the EHR. PHR sponsors include vendors who may or may not charge a fee, health care organizations such as hospitals, health insurance companies, or employers* (Jones et al. 2010, p. 244).

Even though the definition includes the word 'electronic', the task force notes that paper-based PHRs still exist. However, electronic versions were gaining more interest as healthcare moved to electronic formats that offer patients the ability to access their information online (Jones et al. 2010). Even though the definition was suitable for this article – to investigate the state of PHRs – it also has certain features that need to be noted if it is to be used in other contexts. The definition demands that a PHR be secure and private, which is problematic: if a PHR is not private or secure, it still is a PHR, although clearly a sub-optimal one. Likewise, the last part of the definition, which focuses on 'PHR sponsors', is somewhat problematic from the privacy and commercialisation perspectives and should not be included in a definition that is suitable for widespread use.

3.3.9 *Definition by the National Committee on Vital and Health Statistics (2006)*

The beginning of this report (National Committee on Vital and Health Statistics 2006) states that there is no uniform definition for PHR in industry or government in the United States, which makes collaboration and policy-making challenging. The report focuses on offering recommendations regarding PHRs and PHR systems to improve this situation. The recommendations cover areas of privacy, security, interoperability, the federal role, research and evaluation. The report concludes that it is not possible or even desirable to comprehensively define PHR at the time of writing because the concept was still evolving. Instead, the article focuses on characterising PHRs by their attributes.

However, the following statement is quite close to a definition, even if the report's authors choose not to describe it as such: *The Committee proposes adopting the term 'personal health record' to refer to the health or medical record that includes clinical data, and the term 'personal health record systems' to refer to the multi-function tools that include PHRs among a battery of functions* (National Committee on Vital and Health Statistics 2006, p.14). This report's strength is that it acknowledges the challenges of creating a clear definition, especially with a focus on the United States.

3.3.10 *Definition used by Pagliari et al. (2007)*

The short analysis by Pagliari et al. (2007) focuses on the potential of electronic PHRs in England, whose National Health Service's PHR, HealthSpace, was set to become the

world's first full-fledged national system. However, the definition used by (Pagliari et al. 2007) is not their own. Instead, they state that no universally agreed definition for electronic PHRs exists. Still, they use the definition by Markle Foundation (2004b), shortened as follows: *an electronic application through which individuals can access, manage and share their health information ... in a private, secure and confidential environment* (see Pagliari et al. 2007, p.330). Hence, this definition is originally by the Markle Foundation, so any references to Pagliari et al. (2007) are secondary references, which is not desirable if the original source is available, as is the case here.

3.4 Conclusion

As our review and analysis of the 10 most frequently used definitions show, no commonly accepted definitions are used in the literature. Instead, we have several versions at different levels of abstraction. Furthermore, many definitions contradict one another, which is problematic for the field, especially as many articles do not define the term before using it. As noted, some definitions focus more on the desirable features of PHRs, such as a secure environment or the time span of stored information (see e.g. Tang et al. 2006, Markle Foundation 2003). This is problematic as it indicates that if we have a system that is not safe because of a critical vulnerability or if some information is missing, a PHR is no longer a PHR, which is almost certainly not the aim of any author(s). In other cases, there are overly strict limitations in PHR definitions: for example, it must be an online or internet-based tool (e.g. Tang et al. 2006, Li et al. 2013), it must involve a lifelong time span (e.g. Tang et al. 2006, Lafky & Horan 2011), it must be electronic (e.g. Stead et al. 2005, Grossman et al. 2009), or it must be secure (e.g. Jones et al. 2010, King et al. 2016).

4 Proposal for categorising the term PHR

Instead of having one definition for all purposes (which would be too broad) or having an individual definition in each paper, we should have a suitable hierarchy for PHR and its primary variations. This would help us avoid the problems that have arisen due to the lack of a definition. In addition, as we are focusing on the term itself, we are not restricted by the context of a specific research endeavour. We have no actual application or solution that directs our categorisation of definitions. Instead, we offer a hierarchical definition that is based on the different types of PHRs found in our review.

Thus, our proposal for RQ2 (What kind of systematic hierarchy for the term PHR could facilitate a coherent use of the term in the future?) is to categorise the main types of PHR definitions found in the literature at different levels and to create a taxonomy of the different kinds of PHRs.

Our proposal for this hierarchy is presented in Figure 2. The meta-level shows that a PHR is a sub-category in the larger context of overall medical informatics terminology that is beyond this paper's scope. We propose that the first-level definition for PHR should be detailed but leave ample room for different types of PHRs, as compared to the more abstract definitions presented in Table 3.

Thus, our proposal for definition of PHR is as follows:

'A personal health record (PHR) is a representation of information regarding or relevant to the health of an individual (including wellness, development and welfare) which may stand alone or integrate health information from multiple sources, and for

which the individual, or their authorised representative, manages and controls the PHR content, grants permissions for access by other parties and/or shares information directly with other parties’.

This definition is based on the one offered by the International Organization for Standardization (ISO) (International Organization for Standardization 2014), with minor changes (see original in footnote¹).

At the first level of the hierarchy, we do not believe that the definition should contain any statements about what kind of solution or tool a PHR is. If we set overly strict limitations, we may end up in a situation where our definition of PHR contradicts the intuitive idea of PHRs. For example, even though the definition of Markle Foundation (2003) is the most widely used version, we did not see it as suitable because it is too limiting. Demands for PHR to be internet-based and lifelong are too limiting, as we know that there are stand-alone PHRs, and the notion of a lifelong timespan is inherently problematic. Thus, it seems odd that a PHR would cease to be a PHR simply because it was not a lifelong tool.

For clarification, we underline that Figure 2 presents a hierarchy based on inheritance. Thus, upper-level definitions are part of the lower-level definitions to which they are connected. Note also that terms inherit definitions only vertically, not horizontally. Therefore, the first-level definition is built into the second level; similarly, the third-level definition contains the definitions from the first two levels that are connected to it.

The second level of definitions presents PHR types. The types used can be found in several articles: tethered (e.g. Archer et al. 2011, Monsen et al. 2012, Wagner et al. 2012, Ancker et al. 2014), interconnected (or interoperative) (e.g. Tang et al. 2006, Gaskin et al. 2011, Bouri & Ravi 2014) and stand-alone (e.g. Tang et al. 2006, Archer et al. 2011, Gaskin et al. 2011, Demiris 2016), making it a natural choice for the second level of categorisation:

Tethered PHR: *A tethered PHR is a system provided by a healthcare organisation or other service provider that is connected to its host information system and cannot be used without it.*

Stand-alone PHR: *A stand-alone PHR is a PHR that is not designed to be connected to other systems.*

Interconnected PHR: *An interconnected PHR has the built-in possibility of connecting to other systems managed by other parties, but it can be used also without any other systems.*

Tethered PHRs are intrinsic parts of other systems and do not work without their hosts. Interconnected PHRs are a combination of the stand-alone and tethered approaches: while they can be used on their own, they also have built-in interfaces for connecting to other systems, such as official healthcare systems.

The third level of the hierarchy contains the detailed types (see Table 3) and thus helps differentiate between specific solutions.

The descriptive level of this hierarchy is meant for a specific description of the PHR at hand. In the literature, this means that the PHR under focus can be detailed at an appropriate level of accuracy. However, this level is not actually part of the hierarchy; rather, it clarifies the line that signifies the top of the hierarchy proposed here.

The other PHRs and their subcategories are marked with question mark to show that there may be different kinds of PHRs that could emerge and should be included in this hierarchy.

Table 3 Proposal for term definitions

Term level 1	Term level 2	Term level 3	Definition of term	Notes
PHR			A PHR is a representation of information regarding or relevant to the health of an individual (including wellness, development and welfare) which may be stand-alone or integrate health information from multiple sources, and for which the individual, or his or her authorised representative, manages and controls the content , grants permissions for access by other parties, or shares directly with other parties’.	Modified from ISO (International Organization for Standardization 2014)
	Tethered PHR		A tethered PHR is a system provided by a healthcare organisation or other service provider that is connected to its host information system and cannot be used without it.	Inherits the definition of PHR
		Portal-based tethered PHR	A portal-based tethered PHR	Inherits the definition of tethered PHR
		Application-based tethered PHR	An application-based tethered PHR	Inherits the definition of tethered PHR
	Stand-alone PHR		A stand-alone PHR is not designed to be connected to other systems	Inherits the definition of PHR
		Paper-based PHR	A paper-based stand-alone PHR	Inherits the definition of stand-alone PHR
		Digital PHR	A digitally stored stand-alone PHR	Inherits the definition of stand-alone PHR
	Interconnected PHR		An interconnected PHR is a PHR that has the built-in ability to connect to systems managed by other parties but can be used without those systems.	Inherits the definition of PHR
		Portal-based interconnected PHR	A portal-based tethered PHR	Inherits the definition of interconnected PHR
		An application-based interconnected PHR	An application-based interconnected PHR	Inherits the definition of interconnected PHR

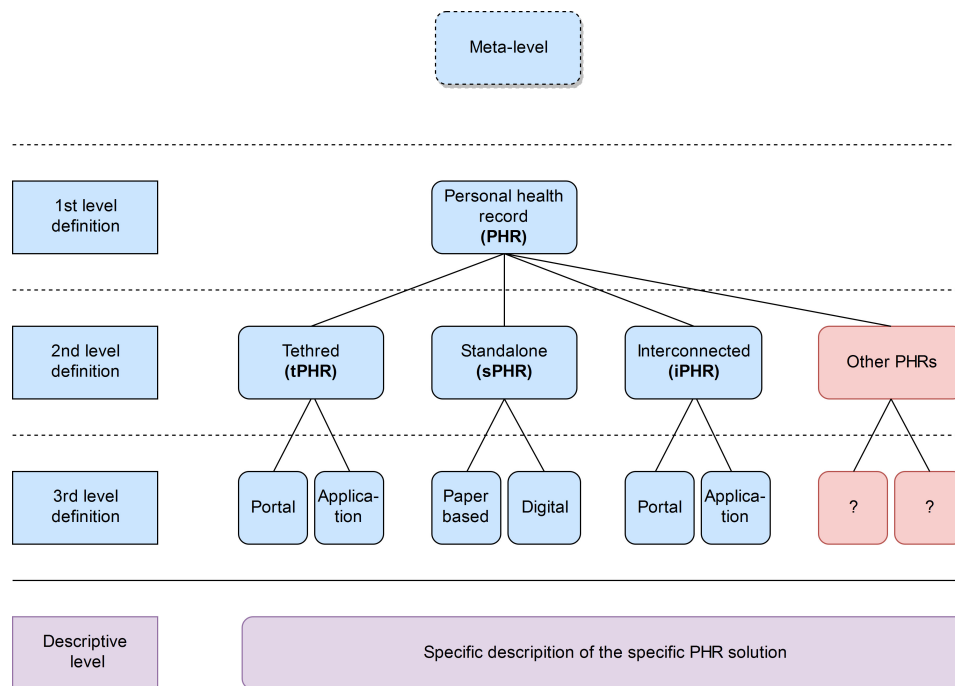


Figure 2 Hierarchy proposal for the term 'personal health record' (PHR).

5 Implications and limitations

The fragmented state of the definitions of 'personal health record' affects the overall progress of efforts to implement, integrate and improve PHRs. For example, one article might use it as an extension of the EMR provided by a hospital, whilst another refers to a USB drive controlled by the patient, and a third describes a portal offered by some third party. In this situation, we simply cannot be talking about the same thing.

Thus, by providing a nuanced categorisation of the term based on an extensive literature review, we offer a way to approach PHRs with a common and explicitly stated and understood meaning. The hierarchy we propose, which combines flexibility with precision, can help compare different studies when systemically evaluating the similarities and differences between PHRs. For example, when analysing how PHRs affect clinical practice, the outcome will likely follow one track for PHRs that are tethered and thus part of an existing system used in a healthcare organisation. That information will likely be compatible with tools that professionals use and therefore supports healthcare professionals' work. By contrast, the stand-alone systems developed to fulfil the needs of individuals in managing their health-related information may not be as valuable for healthcare professionals. The interconnected PHR is a hybrid solution between these two extremes and thus has different aims that vary with the system. Stand-alone, tethered and interconnected PHRs all have advantages and shortcomings.

Hence, if used to define different kinds of PHRs, the categorisation provided here will help researchers analyse existing findings and improve the design of future studies. It reveals the fundamental differences between diverse cases and systems. Our contribution offers the possibility of clarifying research on the topic of PHRs.

However, we note that this research is based on the authors' interpretations. Others could create a different categorisation based on the same review process. There are no precise lines between articles that include a definition and those that do not. Likewise, the categorisation of which definitions are the authors' own, which are referred, and which are cited can be questioned by the reader. However, we believe that our view is plausible and offers a fruitful basis for using the term in the literature, especially compared to the current situation, in which its meaning is all too often left open to interpretation.

6 Conclusions

Based on a systematic literature review and term use analysis, we have found that the term 'personal health record' is commonly used but rarely defined and that when it is defined, it is often too specific and thus excludes some systems that can intuitively be seen as PHRs. The biggest problem is that there are no commonly accepted definitions, even though some definitions are used quite frequently, even as second-hand references. This has led to a situation where we cannot determine with any confidence what is meant by the term.

In response to this diversity and the confusion to which it inevitably leads, we have created a proposal for a hierarchy of PHR-based categories where the term is defined at different levels for different purposes. The hierarchy is based on the findings of our review, and we believe that it offers a systematic proposal on how the term 'personal health record' should be used. However, our hierarchy is a proposal that can be modified or further developed to meet the different communication needs in research and elsewhere. Thus, this article can serve as the opening statement in a discussion that will hopefully lead to more systematic use of the term 'personal health record' and its subcategories.

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