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History and Trends of "Personal Health Record" Research in PubMed

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Objectives: The purpose of this study was to review history and trends of personal health record research in PubMed and to provide accurate understanding and categorical analysis of expert opinions. **Methods:** For the search strategy, PubMed was queried for 'personal health record, personal record, and PHR' in the title and abstract fields. Those containing different definitions of the word were removed by one-by-one analysis from the results, 695 articles. In the end, total of 229 articles were analyzed in this research. **Results:** The results show that the changes in terms over the years and the shift to patient centeredness and mixed usage. And we identified history and trend of PHR research in some category that the number of publications by year, topic, methodologies and target diseases. Also from analysis of MeSH terms, we can show the focal interest in regards the PHR boundaries and related subjects. **Conclusions:** For PHRs to be efficiently used by general public, initial understanding of the history and trends of PHR research may be helpful. Simultaneously, accurate understanding and categorical analysis of expert opinions that can lead to the development and growth of PHRs will be valuable to their adoption and expansion.

Keywords: Personal Health Record, Electronic Health Records, Electronic Medical Records, PubMed, Medical Subject Headings, Review

I. Introduction

Within a relatively short period of time, the Internet has allowed consumers to obtain expert medical/health information and thus the potential to make more informed decisions. As the saying goes, knowledge is power, and consumers are therefore becoming more powerful using health information technology in the form of computers and smart phones that can access the Internet. In today's society, a paradigm shift is gradually occurring from the medical service system and healthcare providers as the holders of medical knowledge to consumers becoming the primary authorities of their own health management. Of course, this situation clearly has its limitations and patients sometimes struggle to interpret the vast quantity of information available, some of which is inaccurate. With this comes increasing responsibility as consumers become more engaged in activities related to healthcare. Personal health records (PHRs), which are driven in part by this paradigm, have the potential to be a critical technological catalyst for healthcare consumers in the 21st century, which may in turn result in improved health.

The history of PHR implementation and application is relatively short, but many efforts to date have focused on recording protocols of disease treatment and health management. In this context, PHRs are older in origin, but its

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realistic application has been relatively recent. PHRs are often linked with electronic medical records (EMRs) and electronic health records (EHRs), which are increasingly widely used, and the increasing use of PHRs has also been driven by the growing digitization of health/medical information. Especially in the American healthcare market, where various different medical information systems are becoming more interconnected, the application of PHRs has grown with concomitant increases in health improvement and disease prevention.

However, active research efforts regarding PHRs are in their infancy, in part due to the lack of consensus about the standard definition of a PHR. The direction of PHR research will become an integral part in making the Lifetime Electronic Health Record a solution for aging societies, which have the large burden of chronic illnesses. To assess these research efforts to date, we searched the literature for research involving PHRs and summarized the results. We also describe how the topics assessed have evolved over time.

II. Methods

In this study, the following methods were used for literature survey. For the search strategy, PubMed, the world's largest biomedical research database managed by the National Library of Medicine (NLM), was queried for 'personal health record, personal electronic health record, electronic personal health record, personal record, and PHR' in the title and abstract fields. Our search returned 695 results, and those containing different definitions of the word 'PHR' were removed by one-by-one analysis. The majority of the removed articles were published in scientific journals in the fields of biology (cell biology, molecular biology), chemistry, bioinformatics, biochemistry, genetics, physiology, nanotechnology, neuroscience, etc., and the acronym PHR often meant something different. For example, reports regarding the 10-year project, "physicians for human rights (PHR)" published in "health human rights" frequently showed up in the search results. In addition to this, definitions regarding consumer-centric trends that reflect the current paradigm shift in the medical field, such as 'participatory health research' and 'partnership for health reform,' were also included in the PHR search results. Further, 'public health research, public health recommendations, public health risk, periodic health review, preventable hospitalization rates, proportionate hospitalization ratios, and physical rehabilitation (PhR)' use the same PHR acronym. In the end, a total of 229 articles were analyzed in this research.

III. Results

1. Changes in Terms Over the Years: Before the Year 2000

The first appearance of PHR in an academic journal was in Germany in 1969 – 'personal record linkage' in Methods of Information in Medicine Supplement among the categories of 'computers, humans, medical history taking, medical record linkage, medical records, and research'. However, earlier papers were not all computerized or in electronic format, and they started out by referring to personal records in the most basic sense. In other words, PHR in a historical context represents a simple form of notes that contains information one needs in order to be informed about one's health, and early studies on PHRs focused on such paper records. Further, from the perspective of community health, health records of certain groups may possess significant meanings. Therefore, even though not digitized, the importance of such records has been recognized. Thus, the 1973 papers on 'Personal health records for young female students' in Japan, and a series of four papers published in March of 1974 under 'Saskatchewan adventure: a personal record,' were the starting points of research fueled by social interest. This conclusion was reflected by 'maternal and child health in the third world. Problems of data collection' (1982), which pointed out the importance of personal records, along with another paper published in the same year called 'pocket-size personal health record.' Additionally, 'personal record of the government-operated public health nursing activities' published in 1983 in Japan was of a similar vein. The papers titled 'personal health record' and 'card file for personal record keeping' published in June of 1983 frequently contained the German words for 'personal record' and 'personal health record.'

1) Shift to patient centeredness

The 'P' for personal in PHR is frequently used as an acronym for 'patient,' with 'patient-held health records' in 1993 marking the start of such usage. In other words, the term 'patient held health record' was first used in 1993, whereas 'patient-held record' was used in 1996, 1998, 1999, 2002, and 2009. Further, the term 'personally controlled health records (PCHRs)' strongly expresses the rights to have control over one's personal records. A similar but not identical example of the use of 'P' as an acronym for 'parent' was published in 1993 in the form of 'parent held record.'

2) Mixed usage

The specific area that PHR refers to has become conflated by continued mixed usage with phrases such as EMR/EHR. In other words, the term PHR started to be accepted as a sepa-

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Table 1. Variable usage of terms about personal health (PHR)

Usages	
'P'	Personal, patient, parent, protected
Combination of terms to form PHR	Personal record
	Personal health record
	Patient-held record
	Patient-held health record
	Personal medical record
	Patient-held medical record
	Personally controlled health records
	Personal electronic health record
	Electronic personal health record
Other terms	Personal health application (PHA), personal health information (PHI), personal health folder, personal health record books, protected health records

rate concept from EMR with the use of phrases like personal medical record (1995) and computer-generated patient-held medical record (1996). This separation from digitized and paper records occurred when computerized records became the standard, and the word 'electronic' was added to PHR in order to distinguish it from past paper records. This is also indicated by terms such as personal electronic health record and electronic personal health record. In the middle of the 20th century, as the discussion of EHRs became increasingly common, the term 'personal' was added to EHR. This was also the period where the phrases personal health application (PHA), personal health information (PHI), personal health folder, and personal health record books came into use. As privacy and security have become more important recently, PHR sometimes refers to protected health records. The various uses of PHR are summarized in Table 1.

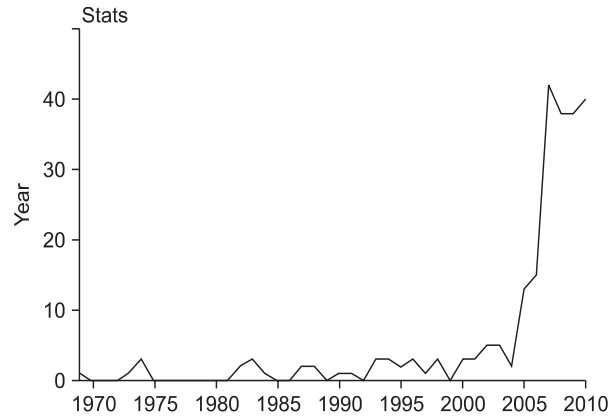

Figure 1. Number of personal health record publications by year.

2. Trends in PHR Research

1) Number of publications per year

As discussed in the previous section, the beginning of PHR research goes as far back as the 1960s but was followed by a period of little endeavor. As the 21st century began the era of widely available information, record formats have changed as well as the level of interest in individuals regarding their health records, resulting in increased interest in the PHR field. Figure 1 shows the number of publications containing PHR per year starting in 1960. In the 1960s, several studies on PHRs per year were published, and this trend remained consistent until the early 2000s, where the number rapidly increased. This trend is the result of the emergence of a patient-centered care paradigm and the acknowledgment of PHR as an important means of patient safety and u-Health. Additionally, the advent of the Internet and information technology has allowed various enhancements in PHR functionality and applications.

2) Major publications

For the 229 articles investigated in this study, the journal with the most publications is the Proceedings of American Medical Informatics Association (AMIA) with 23 articles, followed by 22 articles in Studies in Health Technology and Informatics. The five journals with the most number of PHR publications consisted 36.6% of the total number of journals and they are shown in Table 2.

3) PHR research topics

Among the 229 articles, 53 articles did not have abstracts

Table 2 . Top 5 journals publishing personal health record manuscripts

Rank	Full title	Papers with full text only	Papers including abstracts
1	AMIA Annual Symposium proceedings (AMIA Annu Symp Proc)	23	23
2	Studies in Health Technology and Informatics (Stud Health Technol Inform)	22	22
3	Journal of American Health Information Management Association (J AHIMA)	1	16
4	Journal of the American Medical Informatics Association : JAMIA (J Am Med Inform Assoc)	13	13
5	Journal of Healthcare Information Management: JHIM (J Healthc Inf Manag)	9	10

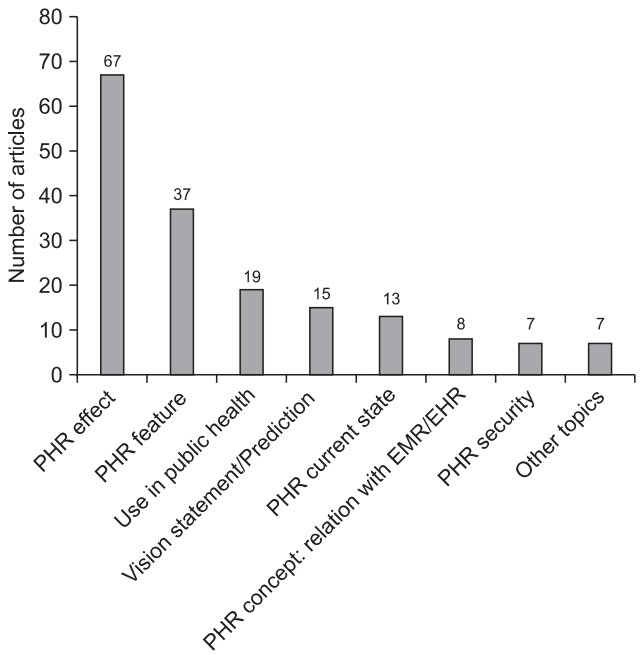

Figure 2. Topic categories of personal health record (PHR) researches.

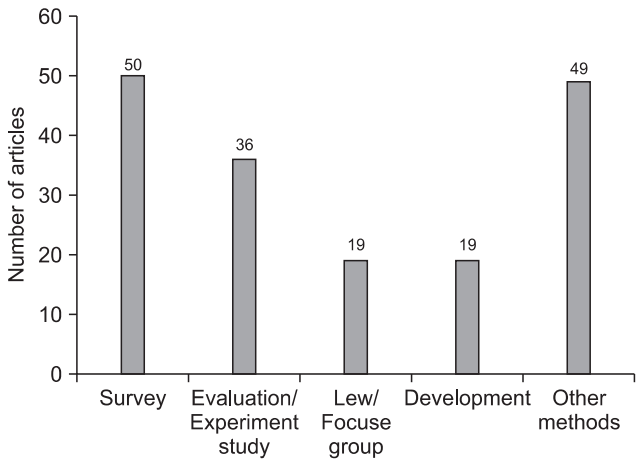

Figure 3. Methodologies of personal health record (PHR) researches.

or the bodies of work available and 4 articles were review papers. The rest of the 172 articles were investigated for their research subjects, methodology, and target diseases. The distribution of research subject/topics are shown in Figure 2, with the effect of PHR in disease and health management being the most frequent, followed by the required features of PHR. Additionally, a number of studies dealt with application analysis in public health, which was initially deemed a crucial function of PHR, and as the history of PHR is relatively short, predictions regarding the future direction and implications of PHR were studied in a number of articles. This can be regarded as having similar characteristics and approaches as the articles dealing with the current status of PHR. Naturally, the PHR literature overlaps at time with that of EHR and EMR, and there are a few articles that clearly distinguish their differences. Additionally, due to the onsent of personal health records, privacy and security issues were more frequently included.

4) Methodologies of PHR researches

The most frequently used methodology in the articles studied is the survey method. The second most frequently used methodology is to analyze and test the PHR, where the focus of the studies is to investigate the various perspectives of PHR users through interviews and focus groups. In terms of PHR being a newly developed record of health management, there were studies on recommending the initial developmental directions. A large portion fell under the 'others' category because of there exists a large number of varied approaches in studying PHR, which reflects the absence of unified approach (Figure 3).

5) Application of PHR: health management vs. disease management

In the articles that address disease/health management functionality of PHRs, 7 articles reported on cancer, 6 on diabetes, and 4 on heart disease. In other words, PHR research is less focused on its use for patients with specific illnesses but rather its role as a health management and promotion tool.

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This reflects the difference between US and Korea. In Korea, device development geared towards heart disease, diabetes and other diseases is gaining popularity along with u-Health, whereas in the US, individuals are more active in finding and pursuing solutions for their own health management. Thus, this difference reflects the medicine market trend of PHRs facilitating personal health management systems. Further, as personal management of health information by individuals is a unique feature of PHR, its wider use must involve collection, storage, analysis, feedback, and self-motivation through everyday use, rather than the health professional being the intermediate manager of information (Figure 4).

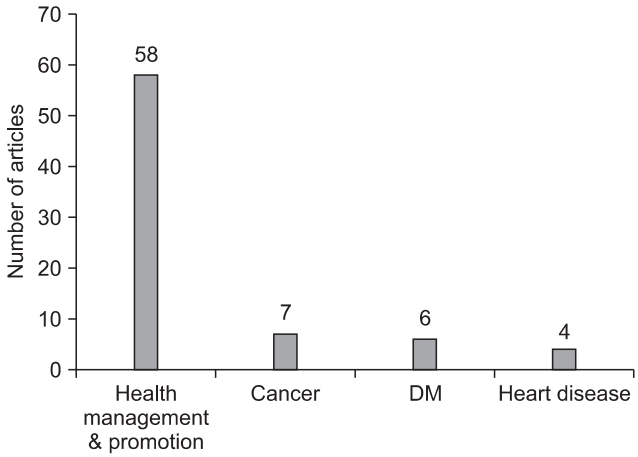

Figure 4. Target diseases of personal health record (PHR) research.

3. PHR Research Trend Observed in Medical Subject Headings (MeSH) Analysis

The PubMed database provided by NLM uses MeSH to briefly introduce each article's findings. Therefore, the main focus of each article can be inferred by studying its MeSH terms, which is one of the approaches used in this study to categorize the findings of the large number of PHR articles. However, some of the older articles were published before MeSH format became the standard, such that only 42 articles out of the 229 studied contained MeSH terms. The frequency distribution of the 1,812 MeSH terms collected from these articles is shown in Table 3. The figure shows the focal interest in regards to the PHR boundaries and related subjects. The most frequently used term was 'computerized medical

Table 3. MeSH terms most frequently used in personal health record (PHR) manuscripts

MeSH terms	No. of publications
Computerized medical records systems	179
Patient access to records 32 + access to information 14	46
Confidentiality 23 + computer security 18 + privacy 1	42
Internet	39
Patient participation 26 + consumer participation 7	33
Medical record linkage 16 + medical records 8	24
Personal health records (PHR)	21
Diffusion of innovation	20
Questionnaires	18
Physician-patient relations 11 + professional-patient relations 3 + nurse-patient relations 1 + interprofessional relations 1	16
User-computer interface	13
Attitude to health, medical informatics, patient satisfaction	Each 12
Attitude of health personnel, communication, electronic health records (EHR), organization and administration, patient-centered care	Each 11
Family practice, software	Each 10
Continuity of patient care, data collection, patient education as topic, self care	Each 9
Delivery of health care, education, forms and records control, information dissemination, quality of health care	Each 8
Attitude to computers, health services, immunization, information storage and retrieval, interviews as topic, measles vaccine, telemedicine	Each 7
Ambulatory care, decision support systems, clinical, health knowledge/attitudes/practice, health plan implementation, health status, patient advocacy, population, public health, systems integration	Each 6

Table 4. Subjects groups of personal health record (PHR) utilization

Subjects groups	No. of publications
Female 38 + women 1	39
Male	35
Middle aged	25
Adult	20
Aged 20 + geriatrics +2, geriatric nursing +2	24
Child 12 + child, preschool 11	23
Infant	15
Adolescent 9 + young adult 1	10
Parents	7
Physicians	7
Disabled persons	6
Military personnel	2
Minority groups/education	1

Table 5. Number of personal health record (PHR) publications by countries

Country	No. of publications
United States	66
Australia (South Australia 4 + New South Wales 3 + Australia 1)	8
UK (Great Britain 2 + London 2 + England 1 + Scotland 1)	6
Canada (Saskatchewan 4 + British Columbia 1 + Canada 1)	6
Germany	5
Europe (Didn't specify countries)	3
France, Japan, Netherlands	Each 2
Asia, Austria, India, Iran, Luxembourg, Mexico, New Zealand, Spain	Each 1

records system (179)' and the subject phrase itself 'personal health record' only appeared 21 times. This, along with the 24 appearances of 'medical record linkage, medical records' indicates that personal health record was not debated over its characteristics but rather as a part of medical records. The next most frequently used term was 'patient access to records, access to information,' indicating an important function of PHRs: giving patients access and rights to their own records and information. An equally important issue is the confidentiality, security, and privacy of information, in anticipation of sensitive and problematic situations that can arise from breach of such issues. 'Patient participation, consumer participation' is also an important PHR characteristic that occurred with sufficient frequency. The fact that one of the applications of PHR has high relevance to public health requires some attention. In actuality, early articles in which PHR started to appear stressed the importance of personal health information in public and school health. This is more evident in the fact that 'primary healthcare, immunization, population, public health, and vaccine' are frequently discussed in these articles.

The subject groups of PHR utilization show that the 'female' group was the most frequent, followed by 'male,' 'middle aged,' 'adult,' 'aged,' and 'child.' This can be interpreted as the notion that women are responsible her family's health and thus are the most active users of PHRs. Recently, u-Health is gaining consideration in servicing the elderly population as they become more comfortable with cutting-edge technology, thereby expanding the utility of PHRs. Another interesting fact is that the parents group used PHRs initially in regards to school health, leading to the acronym PHR referring to 'parent held record' (Table 4).

The US clearly leads in the number of publications on PHRs, followed by Australia, UK, Canada, Germany, and other European countries (Table 5). In Korea, only a few recent articles have been published in domestic journals, and thus no records of them appear in PubMed.

The appearances of diseases in the articles using the MeSH term search were as follows: 7 neoplasm, 4 disease management, 4 emergency service, 3 influenza, 3 stroke, 2 diabetes mellitus (DM), 2 infertility, 2 dentistry, 1 depression, 1 HIV infections, 1 hypertension, and 1 stress. This differs slightly from the interest in the Korean medical field in which DM and hypertension take higher priority, which is a rather new trend in Korea. Further, a small difference in numbers was observed when searched in the actual bodies of the articles, because even though the article deals with DM, they used 'disease management' in the MeSH term.

4. Current Adoption Status of PHR

During our survey of the literature, a 2010 article by Jones et al. on the current status of PHRs was found, and their findings are discussed here. This section is an excerpt from the Medical Library Association (MLA)/NLM study by Jones et al. [1]. The MLA/NLM Joint Electronic Personal Health Record Task Force examined the current state of PHRs. A working definition of PHRs was formulated, and a database was built with fields for specified PHR characteristics.

After examining various existing definitions, they provided the following working definition: "Electronic personal health

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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."

Data elements they found as common characteristics of PHRs are as follows:

- Name of PHR product
- Name of PHR provider
- Contact information for PHR provider
- Category of provider (independent, health insurer, employer, health care provider)
- Enrollment (open to all, open only to provider's participants)
- Web location
- Standalone or integrated
- Sample available for viewing (yes or no)
- Software (open source, freeware, or not available)
- Consumer health information or links to consumer health information (yes or no)
- Information from electronic health record included (yes or no)
- Information downloadable to mobile device (yes or no)
- Marketplace penetration (number of installations, sales, or downloads)
- Platform (Web, Mac, PC)
- Privacy and security features
- Standard support
- Notes

Of the 117 PHRs they identified, they categorized 91 as viable with almost half were standalone products. A number of the PHRs used national standards for nomenclature and/or record structure. Less than half were mobile device-enabled. Some were publicly available, and others were offered only to enrollees of particular health plans or health care organizations or employees at particular institutions. Further, a few were targeted to special health conditions. The PHR field is very dynamic and while most PHR products have some common elements, their features can vary [1].

IV. Conclusions

PHRs, with its increased focus on the medical and IT industries, are rapidly being developed and will soon be at the stage of selection by clinical consumers. For PHRs to be efficiently used by the general public, initial understanding of the history and trends of PHR research may be helpful. Simultaneously, accurate understanding and categorical analysis of expert opinions that can lead to the development and growth of PHRs will be valuable to their adoption and expansion.

Certification of PHRs is necessary for their future adoption and usage and to guarantee their quality. The certification commission for health information technology has recommended certification of the following PHR attributes: privacy, security, interoperability, and functionality [2]. Adoption of national standards will be necessary as they will soon be crucial for interoperability, transportability, and security.

Applications of Health Information Technology to various health problems in modern society are difficult to accurately predict due to their rapid evolution. Nonetheless, PHRs appear to have a key place at the table since they will allow individuals to increase the quality of their lives by managing their own health information. Thus, it is increasingly important for researchers in the healthcare industry to consider development, implementation, and expansion of PHRs and endeavor to accelerate the realization of their full potential for health consumers, especially those with chronic conditions.

Conflict of Interest

No potential conflict of interest relevant to this article was reported.

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