

# Critical Advances in Bridging Personal Health Informatics and Clinical Informatics

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## Summary

**Objectives:** To provide a survey over significant developments in the area of linking personal health informatics and clinical informatics, to give insights into critical advances and to discuss open problems and opportunities in this area.

**Methods:** A scoping review over the literature published in scientific journals and relevant conference proceedings in the intersection between personal health informatics and clinical informatics over the years 2010 and 2011 was performed.

**Results:** The publications analyzed are related to two main topics, namely "Sharing information and collaborating through personal health records, portals and social networks" and "Integration of personal health systems with clinical information systems". For the first topic, results are presented according to five different themes: "Patient expectations and attitudes", "Real use experiences", "Changes for care providers", "Barriers to adoption" and "Proposed technical infrastructures". For the second topic, two different themes were found, namely "Technical architectures and interoperability" and "Security, safety and privacy issues".

**Discussion:** Results show a number of gaps between the information needs of patients and the information care provider organizations provide to them as well as the lack of a trusted technical, ethical and regulatory framework regarding information sharing.

**Conclusions:** Despite recent developments in the areas of personal health informatics and clinical informatics both fields have diverging needs. To support both clinical work processes and empower patients to effectively handle self-care, a number of issues remain unsolved. Open issues include privacy and confidentiality, including trusted sharing of health information and building collaborative environments between patients, their families and care providers. There are further challenges to meet around health and technology literacy as well as to overcome structural and organizational barriers. Frameworks for evaluating personal health informatics applications and pervasive health technology are needed to build up an evidence basis.

## Keywords

Clinical informatics; personal health informatics; personal health records; personal health systems; privacy

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## 1 Introduction

Ongoing developments towards a global information society accentuate the demand for highly individual, personalized solutions. This societal development has also affected health care where not least the Internet has played an important role in enabling patients to access large amounts of information. As patients become better informed their role is changing from a passive consumer into an active participant of the healthcare process. Mobile technology offers new possibilities to provide patients with more knowledge and better tools to keep healthy. The Internet enables delivery of individually tailored health services to patients and citizens on a broad scale.

Institutions, providers, and informaticians now encourage healthcare consumers to take greater control of their own healthcare needs through improved health and wellness activities, internet-based education and support groups, and personal health records [1]. This "consumer empowerment movement" has, as a part of personal health informatics, been driven as an alternative and/or complement to the traditional clinical informatics field. Both fields strive to achieve higher quality and safer care and well-being but focus and goals in clinical respectively personal health informatics are different. The field of Clinical Informatics deals with "the application of biomedical informatics methods to support clinical practice" [2]. The field of Per-

sonal Health Informatics studies the information use of patients and citizens to support self-care, prevention and lifestyle management. Personal health records, patient portals and social networks but also sensor-based health-enabling technologies and personal health systems have been researched in this regard.

Whereas clinical informatics has been a well-established field for several decades, personal health informatics is still in its infancy. One central concept in personal health informatics is the personal health record (PHR), where a patient's health information is organized around the individual. In 2005, the International Standardization Organization (ISO) defined the key features of the PHR to be that "it is under the control of the subject of care and that the information it contains is at least partly entered by the subject (consumer, patient)" [3]. According to this standard, the PHR can be considered in at least four different forms: "(a) a self-contained electronic health record (EHR), maintained and controlled by the patient/consumer, (b) a self-contained EHR, maintained and controlled by a third party such as a web service provider, (c) a component of an integrated care EHR maintained by a health provider (e.g. general practitioner) and controlled at least partially (i.e. the PHR component as a minimum) by the patient/consumer, or (d) a component of an integrated EHR but maintained and controlled by the patient/consumer" [3].

Often PHRs are accessible through patient portals, i.e. healthcare-related online applications or services that are available on the Internet. This sector is growing rapidly and the health care consumer interest, at least in the US, seems to be high towards having online access to medical records and test results, being able to schedule appointments online or accessing general information about health conditions or treatments [4]. However, although some solutions offer ways for information exchange between the PHR and clinical information systems, there is yet no real re-architecting of health care services around the patient [5].

Also advances in pervasive computing technologies [6] have provided a basis for the design and development of personal health systems (PHS) and services, the majority of which rely on the adoption of medical sensors and networking/communication technologies [7]. PHS "assist in the seamless provision of quality controlled, and personalized health services to individuals regardless of location" [8]. Pervasive healthcare comprises the application of pervasive computing technologies and the attempt to change healthcare delivery from organization-centric to patient-centric, from acute reactive to preventive, and from sampling to continuous monitoring [9] with the ultimate goal to become a mean for achieving ubiquitous health [10].

Advances in information technology (IT) are said to enable a fundamental redesign of health care processes based on the use and integration of electronic communication at all levels and to support a transition from institution centric to patient-centric applications [11]. This means, however, that professional health and social care providers need to respond with more patient-centered delivery models to fulfill the increased requirements regarding the quality and accessibility of health and social care services [12].

Our hypothesis is that safe and high quality care can only be achieved if

activities in both fields will be coordinated. This hypothesis is supported by other authors who found that PHRs are not likely to fully support improvements in patient health outcomes if not integrated with EHRs [13-15]. We aim, in this article, to provide an overview over the latest developments and trends in the intersection between personal health informatics and clinical informatics specifically in the following areas:

- Supporting information sharing and collaboration between health and social care professionals and patients through personal health records, electronic health records, patient portals or social networks, and
- Integration of personal health systems with clinical information systems.

The results are expected to illuminate the needs of both areas and to contribute with implications for future research by identifying existing knowledge gaps regarding technical, organizational, legal, ethical and economic issues.

## 2 Methods

We used scoping methods to summarize the research findings in the area of linking personal health informatics and clinical informatics during the last two years. In contrast to a systematic review, a scoping study is not driven by a well specified, often narrow, research question, but applies an iterative search process [16]. This allowed us to extend the number of reviewed papers during the writing of this article with the aim to achieve a broad coverage rapidly.

### 2.1 Search Process

Starting this study, we had no particular research question or were interested of studies with any particular research design but wanted to get a broad over-

view of how the field has developed during the last two years. However, we needed to formulate the most important aspects of the expected results. With the assumption that we would find relevant studies in the common health informatics field as well as in applied technical fields and the social science literature, we started up by searching the following databases: PubMed, ScienceDirect, Google Scholar, ACM Digital Library and IEEE Xplore with the keyword "Personal health informatics" without ". We only searched for papers from the last two years written in English. This search resulted in 481 unique publications. In addition to the studies that appeared in the searches, we also included similar publications, proposed by the database search engine if they were published in the same period of time and seemed relevant from the title. Upon the titles of these publications they were sorted into four different categories, namely "Personal health records (PHR) and Electronic health records (EHR)", "Patient portals and e-services", "Social networks" and "Body area networks (BAN) and Telehealth". These category names were used for a further iterative search. This way, we found additional 30 publications.

### 2.2 Selection of Relevant Studies

Relevant studies were selected by reading the abstracts of all papers that were pre-selected by their title. The only inclusion criteria used was whether the paper was in the intersection between personal health informatics and clinical informatics, i.e. papers that purely dealt with clinical information systems or purely with personal health IT support or social networking services without interaction with clinics were not included. That way approximately 145 publications were selected and more in-depth results from approximately 50 data-driven studies are presented in the results section.

## 2.3 Thematic Coding

To be able to present the results in a structured way, we started with sorting each article according to five presumed categories derived from the technology described, i.e. "patient portal", "EHR or PHR", "social network", "body area network" and "telehealth".

We grouped all articles related to the first three categories under the topic "Sharing information and collaborating through personal health records, portals and social networks" and all articles related to the last two categories under the topic "Integration of personal health systems with clinical information systems".

When reading the pre-grouped articles in their entirety, we used descriptive coding to generate possible themes and compared and contrasted new text with already existing themes. Results are presented according to the emerging themes under each of the two main topics.

## 3 Results

Our results of this review of recent publications in the intersection between personal health informatics and clinical informatics will be presented according to two main topics, namely

- Sharing information and collaborating through personal health records, portals and social networks, and
- Integration of personal health systems with clinical information systems.

### 3.1 Sharing Information and Collaborating through Personal Health Records, Portals and Social Networks

Personal health records and patient portals enable patients to make appointments, view laboratory results, refill medications, and communicate with their physician, pharmacist, or nurse

online, and at the same time contribute to improve healthcare quality and diminish costs [17, 18]. There exists an increased demand from patients to follow up their own care process through patient portals [19, 20], especially for patients with chronic conditions. Portals have the potential to diminish social disparities and to increase patients' knowledge levels. It is important however to ensure that patients understand patient portal features and receive follow-up reminders [21]. There is also the possibility that the adoption rate of portals, and participation in social networks increases among members of ethnic minorities [19, 20], and for underserved and specialized groups of patients like the elderly [22].

There have been attempts to specify data and features needed in PHRs such as the work with the Sunnybrook's MyChart PHR. MyChartPHR is a direct extension of the hospital's electronic health record, that evolved into a set of emergent best practices regarding the handling of patient information, access control and consent management as well as additional services such as decision support [23]. Nevertheless, a review of ninety-one different PHRs revealed a large variety of included features [24,25] ranging from overall health histories to particular aspects of health serving specific populations. Fifty-four percent of the PHRs studied were standalone products and forty-nine percent had consumer health data included. Some PHRs were tethered to clinical EHRs with only a few following existing standards. In Taiwan, a PHR system was designed that allows patients to receive data from 10 participating hospitals via a USB flash memory device [26]. The business models used also varied. Chen proposes a 'holistic' view on business models with four interrelated perspectives; service, technology, organization and finance [27]. An alternative way to describe the business model for PHRs is using a subsidization principle. The subsidization principle is based on the assumption that one

party has a considerable interest in giving another party subsidized or easier access to a service, e.g. insurance companies that want their policyholders to track their health status in a personal health record, or hospitals that are interested in having an electronic medical report (e.g., including a patient history, diagnostic findings etc.) from all of their referring doctors [28]. Another alternative is the "crowdsourcing" model used by governmental and local authorities with the assumption that the services to be delivered are of importance for the society. Thus more and more users might get attracted by the possibility to extend the service and create real value for other users [29, 30]. An altruistic view of user behavior does, however, make this principle difficult to apply in for profit organizations.

To develop a sustainable and successful business model for PHRs, it will be necessary to extend the value chain management and to stimulate drivers of customer value creation. This must also include the external environment in which patients interact including political, legal, socio-cultural, technological, economic and demographic issues [31].

#### 3.1.1 Patient Expectations and Attitudes

Numerous surveys report that patients in the U.S. are interested in secure messaging and eVisits with their physicians, online appointment scheduling and reminders, and online access to their laboratory and radiology results [25]. A survey of 214 low-income, ethnically diverse consumers in New York State [32] showed an interest in PHRs comparable or higher than nationally representative populations, provided these systems address privacy and security concerns. The same population's support for health information interchange between care providers was lower however.

Data protection and data security are also the main concerns formulated by 496 German and Austrian citizens that

were interviewed in two metropolitan areas. Up to 75% of the people surveyed collect and store medical documents at home, mainly in paper-based form and mentioned the electronic vaccination record, administrative online information on doctors and hospitals and the administration of appointments and reminders as most valuable features of a PHR [33]. 80-90% of the same respondents were also supportive of health information exchange between care providers.

Patients also expect to get legible information. They must be able to understand the content of their EHR. Slaughter et al. developed a hyper-linked consumer health dictionary to provide easily accessible definitions to patients reading their EHR as opposed to just translating the text into a patient-friendly version [34]. To support patients in entering coded family health histories, more than 2500 synonyms were generated for more than 500 unique disease concepts through multi-source sampling in another project [35].

### 3.1.2 Real Use Experiences

Studies focusing on the use of portals and social networks to deliver virtual services often report high satisfaction rates among patients who have followed a form of "Virtual treatment" and report an impact on the patient-health professional relationship. Fifty-seven severe and very severe COPD patients included in a tele-rehabilitation programme, for example, expressed the view that their relationship with healthcare professionals had developed into a mutual learning relationship. Observations of the same patient group showed further that patients tended to become more active as they participated in the programme [36]. Demiris and Thompson advocate shared decision making as an ideal model of treatment decision-making in the clinical encounter and especially in geriatric care that involves older adults and their families [37].

Improved quality of life, less in-person consultations, greater knowledge, and better self-management are mentioned as the driving forces of patients' satisfaction with portal- and social network-based applications [38]. Checking laboratory results and pharmacy-related data including prescription renewals were reported to be the features most frequently accessed [39].

The MyHealthVet personal health record has been in use since 2003, giving veterans access to their personal health information and a number of online services. A user satisfaction survey conducted since 2007 reveals that 56% of the 100 617 respondents agree that the use of MyHealthVet has improved their ability to manage their health. Respondents indicated that the main additional features they desire are the ability to view upcoming appointments, to be able to schedule or change their appointments, to view information from their medical record, and to have secure online communication with their doctor [39].

In another pilot project, a personal health record was tethered to the Military Health System leveraging standardized Continuity of Care Documents to either Microsoft® HealthVault or the Google® Health Infrastructure. Results from that project revealed a number of technical challenges such as system performance and the full implementation of standards, as well as additional challenges related to tension between the access to health information requested by consumers and organizationally adopted business practices [40].

In another study, 270 children and adolescents with congenital cardiac disease and their families were given access to a web-based multimedia EHR during and after hospital stay. The adoption rate was high (93%) and users accessed the system more often while patients were in hospital than after discharge. Images were viewed significantly more frequently than text and families also continued

accessing the data in case a patient died after his/her death, probably as part of the grieving process [41].

A literature review about electronic symptom reporting by patients revealed cancer and lung disease patients as the largest diagnostic user group [42]. Contexts of use included complex and long-term diseases, sensitive situations that were often complementary to face-to-face encounters, and follow-ups after surgery that were used as substitute for a clinical consultation.

### 3.1.3 Changes for Care Providers

Even though PHRs are meant to be patient-centered, they are often managed out of a care provider perspective and there is still a high potential for improvement. Semi-structured interviews with seven large early PHR adopter organizations were performed to assess the patient-centeredness of PHRs. These interviews revealed that no organization allows patient views of clinical progress notes, and that the turnaround times for PHR reporting of normal laboratory results can be up to 7 days [43].

In the Netherlands, however, the shift towards patient-centered care has resulted in real changes in the care delivery system. The funding concept for chronic diseases is based on clinical standards and supports collaborative work as well as active involvement of the patient and her informal carers [44]. Hence incentives in the care delivery system are meant to gradually shift from price orientation to be based on quality performance.

To understand some of the consequences of bringing patient-generated data into health care delivery, the temporal and cognitive burden on healthcare staff associated with new workflows has been simulated and estimated to lead to a 29% increase in daily labor costs and 28% shrinkage of the margin between revenues and labor costs [45].

### 3.1.4 Barriers to Adoption

Even with increasing availability of PHRs and a documented consumer interest, the actual adoption of PHR systems is not that high. Several studies have thus looked into this paradox between interest and adoption in order to identify barriers and challenges.

Low PHR adoption has often been explained as a consequence of technology acceptance, varying EHR architectures and vendors, lack of interoperability standards and/or care provider resistance. The main concern however perhaps lies in the premise of ethical and security issues. Several authors [46-49] assert that many patients are more worried about data protection and security, privacy and confidentiality than any other difficulty.

This is supported by an evaluation of ten diabetes-related social network sites that revealed varying quality and gaps in internal and external review procedures. Technological safety was poor, and poor readability of privacy policies was found to impede risk communication [46].

Personal health records and personal health application implementations invert the long-standing paradigm of health care institutions as the authoritative data-holders and data-processors in the system [49]. Patient-centricity brings new benefits to patients but also entails new responsibilities. Cushman et al. [49] summarize for example the following implications for law, policy and practice:

#### Privacy Concerns

- due to a lack of granularity-of-control for patients about what data to share with whom;
- regarding ubiquitous monitoring;
- regarding personal health disclosures about someone else in social networks.

#### Liability Issues

- legal uncertainty regarding non-traditional actors, e.g. when non care professionals reveal someone else's health information or when patients

withhold data from professional health care providers. How should proxy access to a patient's data (e.g. children, elderly) be dealt with [50].

Findings from the same project "Project HealthDesign" by other authors [50] accentuate "personal control of privacy choices", "management of privacy in home conditions", and "rebalancing power structures in shared decision making" as major challenges.

### 3.1.5 Proposed Technical Infrastructures

To tackle the problem of fine-grained access control, Steele and Min propose a role-based access control architecture for portable PHRs based on a signed extended digital certificate [51] and Sujansky et al. provide algorithms for an access control mechanism based on eXtensible Access Control Markup Language (XACML) through standard relational database queries [52].

Weitzman et al. stress the importance of a personally controlled health record (PCHR) system platform that is based on the chronic care model and its possibilities for supporting a new class of patient-facing applications for adolescents with diabetes [47]. Other authors see the possibility to create self-management applications based on PHR data [53] to avoid integration and interoperability issues. Similarly, mobility is an issue and a standard for a portable personal health summary for travelers is proposed [54] and mobile information needs of cancer patients are researched [55].

## 3.2 Integration of Personal Health Systems with Clinical Information Systems

The papers that were analyzed under this topic were usually more technical. Many of them dealt with architectures for pervasive healthcare and the implications for interoperability as well as for security, trust and care delivery.

### 3.2.1 Technical Architectures and Interoperability

Blobel [56, 57] presents an architectural approach with special focus on ontologies and knowledge representation to enable the paradigm changes from organization-centric healthcare to person-centric health. Tuomainen and Mykkänen describe a reference architecture of application services for personal wellbeing information management that is composed of SOA services according to a generic service classification in relation to the Finnish national programme for citizen e-services [58]. Yuksel and Dogac provide a solution to increase interoperability between medical device data and clinical information systems [59]. They used the ISO/IEEE 11073 Domain Information Model (DIM) to derive an HL7 v3 Refined Message Information Model (RMIM) of the medical device domain which they further mapped to some of the HL7 v3-based standard interfaces such as HL7 Personal Health Monitoring Report (PHMR). Koutkias et al present a personalized framework for medication treatment management in chronic care [60] and Fayn and Rubel propose a mobile infrastructure for cardiac disease management [61]. To meet the emerging trends to open, distributed and user-centric telehealth architectures, Koster et al propose an end-to-end approach to security and present a design for consent management in the context of the Continua Health Alliance architecture [62].

### 3.2.2 Security, Safety and Privacy Issues

Ruotsalainen et al. analyzed the way security and trust are implemented in today's healthcare and come to the conclusion that it cannot guarantee information autonomy and trustfulness in pervasive health [63]. They propose a framework model formulating principles for trusted information sharing that include the data subject's right to dynamically verify trust and to control the use of her health information as well as the right to set situation based context-aware policies.

## 4 Discussion

Analyzing the literature of the last two years we can state that, although much work has been done within the respective field of either personal health informatics or clinical informatics, the need for integrating both fields is obvious as we will not achieve patient-centered safe and high quality care and prevention without integrating the existing clinical information about the individual and complementing it with his/her own measurements. There are today many developments with tethered PHRs that provide this kind of functionality. However, these are usually restricted to one care provider organization, and are thus not applicable to patients with several care contacts with several care providers, a situation that may lead to increased safety risks if available information is trusted but knowledge about possibly missing information is lacking. A major issue in this context is the fact that interoperability issues between clinical information need to be solved to provide safe personal health informatics. We found numerous papers describing patient expectations towards PHRs and patient portals [25, 32-35] but albeit this knowledge current PHRs do not always fulfill these expectations. For example, we do know that lab result reporting is one of the most wanted features but few PHRs deliver them in a timely manner [43], if at all. This situation is related to different care provider policies releasing information to patients first if this information cannot harm the patient where the risk of harming is defined by care providers and not patients. This means personal health informatics definitely also increases patients' responsibility.

In general, regarding PHRs there is no evidence base for a set of patient-specific data elements to be included and there is a discrepancy between patients' needs and the elements provided by for example commercial, portable PHRs [64].

However, personal needs differ, and a sensitive issue where we observed large differences between populations relates to privacy and confidentiality issues. In this area a lot of research is currently ongoing and solutions for controllable and trustable information sharing and consent management are mandatory. This is also highly important since citizen-centered health is based on a holistic approach that comprises both health and social care. Such an approach involving not only patients and care providers but also increasingly family and informal carers are promoted [65], and personal health informatics systems are proposed to be extended to the family managed by the middle generation [66].

Despite recognition that personal health informatics applications in general and social media in particular are viewed by consumers as crucial resources for consumer health information, data is lacking on the value or impact of these resources on a) cost-effectiveness b) risk and c) trust and confidence in eHealth services. An important issue to determine is how ready eHealth is to meet citizen expectations and when it will be possible to design secure infrastructures that handle high volumes of genetic, biomedical, clinical and public health information in order to deliver personalized health services.

### 4.1 Limitations of the Study

Although we tried to give an as broad overview as possible, the study is limited to the developments of the last two years. Given the potential delay in publication this means, of course, that there could be other emerging trends and developments that are not captured yet. It is also important to note that we did not analyze the quality and/or methodological approach of the reviewed papers but present study results as they are. We do, however, enlighten contradictory findings between similar studies.

## 5 Implications for Future Research

A number of gaps were identified in the most recent literature that we read for this review. Regarding the availability of clinical information for patients, Collins et al. for example highlighted an important gap between current practices of organizations that support PHRs and a set of standardized "best practices" for making data available for patients online [50].

Arnrich et al. highlight some of the challenges to be solved regarding pervasive healthcare, such as the reliability of long-term monitoring systems, the role of prevention as a key element to maintain lifelong wellness and the need of more advanced design and evaluation methods for ubiquitous patient-centric technologies [10].

Ruotsalainen et al. call for new data models for personal health information and new architectures which support situation depending trust and privacy management [63]. Blobel addresses ontology coordination between disciplines as a crucial demand [56].

Demiris and Thompson emphasize the needs to extract meaningful information from Smart Home and Ambient Assisted Living systems to support decision making [37].

There is still a lack of standards in PHR specifications, which given the diversity in implementing PHRs in real contexts, the sharing of patient information between service providers, across clinical specialties and within the patient's network poses a host of technical challenges [67]. There also arises a complementary need of a legal, ethical and organizational value-based framework. Several studies also accentuate the need for better evaluation studies. In general, results show a number of gaps between the information needs of patients and the information care provider organizations provide to them as well as the lack of a trusted technical, ethical and regulatory framework regarding information sharing.

## 6 Conclusion

Despite different focus and goals between the areas of personal health informatics and clinical informatics, both share common principles and the long-term aim to enhance quality of care for the individual. However, as opposite sides of the same coin, both fields have diverging needs. To support both clinical work processes on one hand and empower patients to effectively handle self-care on the other hand, a number of issues remain unsolved. Open issues include privacy and confidentiality, including sharing of health information and building collaborative environments between patients, their families and care providers. There are further challenges to meet around health and technology literacy as well as to overcome structural and organizational barriers. Frameworks for evaluating personal health informatics applications and pervasive health technology are needed to build up an evidence basis.

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