

Personal Health and Consumer Informatics

A. Guardia¹, C. Boyer², Section Editors for the IMIA Yearbook Sections on Personal Health Informatics and on Consumer Informatics

¹ Dept. of Medical Imaging and Information Sciences, Division of eHealth and Telemedicine
Geneva University Hospitals, Geneva, Switzerland

² Department of Medico-economics Affairs, Geneva University Hospitals, Geneva, Switzerland

² Health On the Net Foundation, Geneva, Switzerland

Summary

Objectives: To summarize current outstanding research in the field of Personal Health and Consumers Informatics.

Methods: A selection of excellent research articles published in 2011 in the field of Personal Health Informatics and Consumer Informatics.

Results and Conclusions: This selection of articles shows that Personal Health Informatics is changing. Indeed, the different solutions tended to the doctors and their interaction, but also tended to the patient in order for him to be more active in his own medical healthcare. The consumer section highlights the development of the social network and the possible limitations.

Keywords

Personal health informatics, consumer informatics, personal health record, smartphone, , social networks..

Yearb Med Inform 2012;25-9

Introduction

Substantial evidence show that patients are involved in health information technology systems to have important information about their health, their families' or friends' health and healthcare. The influence of these technology resources in patient's decisions and actions in their health management and improvement is notable [1, 2, 5].

Consequently, one of the key mechanisms that allow a better patient care by the health care providers and also by the patients themselves can be the Personal Health Information systems (PHI). The physicians using mobile phone applications for example, can monitor patients with chronic heart failure, detect early signs of arrhythmia or ischemia and potentially avoid an imminent heart attack.[4, 6] Of course, the patients themselves can also use mobile phone applications to keep a physical activities history and to point out physiological markers relevant to their health status [6].

Another tool for individuals to be part of their health care is the use of Personal Health Record (PHRs). PHR is used to make medical records and other relevant information available to the patients and, in addition assisting patients in their health management. In one hand, PHR can potentially improve the way health systems interact with patients, in other hand; the physicians have a complete and better view of their patients' health.[2]

Finally, a lot of PHR systems functionalities are made for physicians and not for patients. In order to help patient in health self-management and disease prevention, and as improvements in health outcomes are expected, those functionalities must be patient-oriented and integrated information to the consumer [1, 2, 3]. A better informed patient contributes to improve its management of care. Studies conducted on cancer have shown that patients had better adherence to treatment if they were better informed [7]. Having access to quality health and medical information online does not only improve doctor-patient communication and the quality thereof, but also supports decision-making for patients, caregivers and healthcare providers.[8] If the available information on the Internet is of poor quality or lacks transparency, the consequences can be dangerous and in some cases compromising the health of citizens. A conducted impact study showed that only 0,6 % of the websites assessed take into account the basic, ethical standards to provide trustworthy information [9].

Best Paper Selection

This year the sections Personal Health Informatics and Consumer Informatics have been combined in the IMIA Yearbook 2012 as more and more these two topics are complementary

and closely interconnected. This year we selected for in total seven papers demonstrating the progression of each domain (table 1). A brief summary of these articles is provided in the appendix section.

Conclusions and Outlook

This year, the selected articles for the IMIA Yearbook 2012 show that the Personal Health Informatics is more and more patient-oriented. Effectively, in the first selected article, PHR functions and properties that are important for the patient in order for him/her to improve his/her knowledge and autonomy have been identified. The article, also, gives a list of PHR products available on the market. In addition, it appears in the article that none of the PHRs use existing medical standards for the communication and the storage of their data. Even if for the common features for the areas as structured data, services, security or interface domain, there has been good support.

It will be important in the future to implement the medical standards in the PHRs for patient empowerment and also, in order to provide interoperability and health services allowing the patients/users to choice to use or not a PHR [2].

The second article shows that patients' quality of life and well-being can be improved by the consumer health information technologies (CHITs). It can also increase medication adherence, facilitate the healthcare delivery process and support home care patient self-management. Obviously, those benefits depend on the acceptance of this technology by the current patient users. The patient can for example have had badly past experiences or feel that the technology doesn't reach his/her needs or finally doesn't match with his/her existing values.

Following the results it has been demonstrated that the patient will increase his/her will to use the CHITs if the system applications are in harmony with patients' needs [3].

Table 1 Best paper selection of articles for the IMIA Yearbook of Medical Informatics 2010 in the sections 'Personal Health and Consumer Informatics'. The articles are listed in alphabetical order of the first author's surname.

Section Personal Health Informatics
<ul style="list-style-type: none"> ▪ Archer N, Fevrier-Thomas U, Lokker C, McKibbin KA, Straus SE. Personal health records: a scoping review. <i>J Am Med Inform Assoc</i> 2011;18:515-22. ▪ Helmer A Lipprandt AM, Frenken T, Eichelberg M, Hein A. Empowering Patients through Personal Health Records: A Survey of Existing Third-Party Web-Based PHR Products. <i>electronic Journal of Health Informatics</i> 2011;6(3):e26. ▪ Hussein WI, Hasan K, Jaradat AA. Effectiveness of mobile phone short message service on diabetes mellitus management; the SMS-DM study. <i>Diabetes Res Clin Pract</i> 2011 Oct;94(1):e24-6. ▪ Or CKL, Karsh B-T, Severison DJ, Burke LJ, Brown RL, Flatley Brennan P. Factors affecting home care patients' acceptance of a web-based interactive self-management technology. <i>J Am Med Inform Assoc</i> 2011;18:51-9.
Section Consumer Informatics
<ul style="list-style-type: none"> ▪ Bender JL, Jimenez-Marroquin MC, Jadad AR. Seeking Support on Facebook: A Content Analysis of Breast Cancer Groups. <i>J Med Internet Res</i> 2011;3(1):e16. ▪ Lawrentschuk N, Sasges D, Tasevski R, Abouassaly R, Scott A, Davis I D. Oncology Health Information Quality on the Internet - a Multilingual Evaluation. <i>Ann Surg Oncol</i> 2011;19(3):706-13. ▪ Thompson LA, Black E, Duff P, Paradise Black N, Saliba H, and Dawson K. Protected Health Information on Social Networking Sites: Ethical and Legal Considerations. <i>J Med Internet Res</i> 2011;13(1):e8

The third article shows the feasibility of short message service (SMS) usage between the clinic visits and to evaluate its effect on glycemic control in uncontrolled type 2 Diabetes Mellitus subjects. The results are more than positive and the patients tended to accept the SMS system [5].

The objective of the fourth article is to describe existing electronic and paper-based PHR research and to determine whether PHRs can provide benefits to consumers/patients. They found many relevant papers, indicating a generally growing interest in PHR use, but there is much more to be done in tailoring PHRs for patient health self-management and sustainability.

With the objective to help patients to become more informed, to be part of his/her own health care and also improve efficiencies, it has to be considered that one of the critical role is the Patient-facing. In the future, one of the main problem to solve will be to identify the most useful and effective technologies for patients.

The tendency of the related articles for Consumer Informatics is the more and more preminent usage of social network in the health domain. The qual-

ity issue is still a topic which is constant over the years as Health information of Quality is part of the care and this is more and more established.

The two first articles are related to social network and particularly to Facebook. The first one try to lay out the tendency of the usage of such social network and the second article emphasizes one of the important research implications which is the privacy policy. The second article presented in the appendix section addresses the aspect related to the protected health information on social networking platforms. Quality of health information online is a continuous topic which over years become more and more important but which is still not properly addressed by the different key players world-wide. The last article is regarding the heterogeneity and variability of the quality of health information online amongst different countries.

Acknowledgement

I greatly acknowledge the support of Martina Hutter and of the reviewers in the selection process of the IMIA Yearbook.

References

1. Ahern DK, Woods SS, Lightowler MC, Finley SW, Houston TK. Promise of and Potential for Patient-Facing Technologies to Enable Meaningful Use. *Am J Prev Med* 2011;40(5S2):S162-S172.
2. Helmer A, Lipprandt AM, Frenken T, Eichelberg M, Hein A. Empowering Patients through Personal Health Records: A Survey of Existing Third-Party Web-Based PHR Products. *electronic Journal of Health Informatics* 2011;6(3): e26.
3. Or CKL, Karsh B-T, Severtson DJ, Burke LJ, Brown RL, Flatley Brennan P. Factors affecting home care patients' acceptance of a web-based interactive self-management technology. *J Am Med Inform Assoc* 2011;18:51-9.
4. Hussein WI, Hasan K, Jaradat AA. Effectiveness of mobile phone short message service on diabetes mellitus management; the SMS-DM study. *Diabetes Res Clin Prac* 2011 Oct;94(1):e24-6
5. Archer N, Fevrier-Thomas U, Lokker C, McKibbin KA, Straus SE. Personal health records: a scoping review. *J Am Med Inform Assoc* 2011;18:515-22.
6. Klasnja P, Pratt W. Healthcare in the pocket: Mapping the space of mobile-phone health interventions. *J Biomed Inform* 2012 Feb; 45(1):184-98 doi:10.1016/j.jbi.2011.08.017.
7. Coulter A. Evidence on the effectiveness of strategies to improve patients' experience of cancer care. Oxford: Picker Institute; 2007. p. 6-7. Available from: http://www.pickereurope.org/Filestore/PIE_reports/project_reports/Cancer_reform_strategy_Macmillan.pdf
8. B. Stivilia B, Mon L, Yi YJ. A model for online consumer health information quality. *JASIST* 2009;60(9):1781-91. Available from: <http://dx.doi.org/10.1002/asi.21115>, p. 2,
9. Laversin S, Baujard V, Gaudinat A, Simonet MA, Boyer C. Improving the transparency of health information found on the internet through the HONcode: an impact study, *Stud Health Technol Inform* 2011;169:654-8.

Correspondence to:

Célia Boyer
Health On the Net Foundation
C/o HUG Belle Idée, 2 Chemin du Petit Bel-Air
CH-1225 Chêne-Bourg
Switzerland
Tel: +41 22 372 6250
Fax: +41 22 372 8885
E-mail: Celia.Boyer@HealthOnNet.org

Appendix: Content Summaries of Selected Best Papers for the IMIA Yearbook 2011, Section Personal Health Informatics*

Helmer A, Lipprandt AM, Frenken T, Eichelberg M, Hein A

Empowering Patients through Personal Health Records: A Survey of Existing Third-Party Web-Based PHR Products
electronic Journal of Health Informatics 2011;6(3):e26

The patient's health state is positively influenced by allowing patient to be part of their own healthcare. The PHR functions and properties that are important for patient autonomy have been identified in this survey. It also compiles a list of PHR products available on the market

The main point of this study was to examine the correlation between patient empowerment and the use of these currently available products. Another point was to give advice for further enhancement.

After long research, hard work and based on a literature review, a function taxonomy checklist including 6 domains and 58 subgroups of features was created. Products have been listed from two public directories that list PHRs but also from a explorative search realized using various search engines. A questionnaire have been used to analyze every product and be sent to the product vendor, the public available information about the product, and whenever possible by the exploratory use of provided test accounts.

In general, the PHRs used by the product vendors show a comprehensive

set of means to enter structured data the product vendors. In addition, among the qualities of the entry methods, big differences appear. Only a small number of products have prevented users to use their system daily due to technical barrier. Many interesting services have been pointed out in those questionnaires, especially within the information acquisition and representation domain.

A secured acces of the user to the PHR is the most important requirement revealed by almost all providers.

The next steps in empowering patients will be to help the users by implementing functions with explanatory texts, for example, in entering data or in how this information can be obtained. It appears that only a few products need support for standard medical document formats or protocols. As the standards are stable in time and allow the exchange of data with the entire medical world, it is very important to implement these standards. In addition, the implementation will permit further processing.

Or CKL, Karsh B-T, Severtson DJ, Burke LJ, Brown RL, Flatley Brennan P

Factors affecting home care patients' acceptance of a web-based interactive self-management technology

J Am Med Inform Assoc 2011;18:51-9

In this study, consumer health information technologies (CHITs) refer to patient-focused interactive web- or technology-mediated applications that are designed to improve information access and exchange, enhance decision making, provide social and emotional support, and facilitate behavior changes that promote health and well-being. With the advent of personal health records and other patient-focused health technologies, the factors that are necessary for the acceptance and the use of such innovations needs to be better understood. For the authors, the basis for determining what predicts patients' acceptance (measured by behavioral intention) and perceived

* The complete papers can be accessed in the Yearbook's full electronic version, provided that the article is freely accessible or that your institution has access to the respective journal.

effective use of a web-based, interactive self-management innovation among home care patients is the Unified Theory of Acceptance and Use of Technology.

The method used to measure the acceptance was a questionnaire based on validated measurement scales from prior research. It has been completed by 101 participants as part of the parent study protocol. Latent variable modeling with item parceling guided assessment of patients' acceptance.

The study demonstrates that the factors that influence the patients' acceptance self-reported use of the web-based self-management technology tended to be: perceived usefulness, perceived ease of use, subjective norm, and healthcare knowledge.

Hussein WI, Hasan K, Jaradat AA

Effectiveness of mobile phone short message service on diabetes mellitus management; the SMS-DM study

Diabetes Res Clin Pract 2011 Oct;94(1):e24-6

To facilitate the care of a diabetic patient includes informing the patients on monitoring their blood glucose, their weight, their physical exercise, their diet and diabetes complications. This could take considerable time in the restricted clinic visit. By using integrated portable telemedicine system the communications between patients and their medical team improve a better coaching and could allow taking corrective actions.

The following clinical test confirms the improvement. For the test, 34 adult diabetics were followed. Some criteria have been taken into account: new clinic type 2 diabetes mellitus case, the patient have to be 18 or more, on oral medications or/and Insulin with poor glycemic control (A1c \geq 7,5%). The Two groups were constituted: Control group 22 patients and the interventional group (12 patients). In the last group, two mobile phones have been provided. The clinicians and the educators could send unlimited free SMS between the clinic visits. Their SMS

use id to solve problems, support patients' needs, improve skills, and action plans while contacting the team anywhere and at any time.

The results showed significant reduction in the A1c of the interventional group using continuous and individualized SMS support. However, the observed positive effects may have been influenced by a small group size.

Archer N, Fevrier-Thomas U, Lokker C, McKibbin KA, Straus SE

Personal health records: a scoping review

J Am Med Inform Assoc 2011;18:515-22

The objective of this paper is to review the literature on PHRs and to describe the design, functionality, implementations, applications, outcomes, and perceived and real benefits of PHRs, with an emphasis on experience in the USA and Canada.

From literature, they found the following themes: Primary care physicians play a key role in the management of their patients' health. Many PHR systems are physician-oriented, and do not include patient-oriented functionalities. People with serious chronic conditions, individuals with disabilities, parents with small children, people with a strong interest in maintaining healthy lifestyles, and the elderly or their caregivers are more likely to adopt PHRs. Applications that provided individual tailoring, personalization, and behavioral feedback had the most significant impact on patient health outcomes. Randomised controlled trials are needed to test assumptions about the comparative effectiveness of PHRs on outcomes for various patient populations, using systems designed specifically for patient health self-management and disease prevention.

In conclusion, they found many relevant papers, indicating a generally growing interest in PHR use, but there is much more to be done in tailoring PHRs for patient health self-management and sustainability.

More research is also needed that addresses the current lack of understanding of optimal functionality and usability of these systems, and how they can play a beneficial role in supporting self-managed healthcare.

Section Consumer Informatics

Bender JL, Jimenez-Marroquin MC, Jadad AR

Seeking Support on Facebook: A Content Analysis of Breast Cancer Groups

J Med Internet Res 2011;3(1):e16

Social network websites like Facebook have been growing in popularity as a convenient way of exchanging information and giving/receiving support. There are a lot of emergent support groups related to various health issues like for example breast cancer.

The goal of this study was to characterize the purpose, use, and creators of Facebook groups related to breast cancer.

Authors' methodology consisted on analyzing all Facebook's groups related to breast cancer, operated in English and publicly available on November 19, 2008, the date the study began. They have extracted information on the administrator, purpose of the group and the number of user-generated contributions, and analyzed the content following developed coding scheme.

The study had given rise to the analysis of 620 breast cancer groups on Facebook, and the total of 1'090'397 members.

The identified purposes of creation of such groups were following: fundraising (44.7%), awareness (38.1%), product or service promotion related to fundraising or awareness (9%) and patient/caregiver support (7%).

Regarding the number of members, the most popular was awareness groups with 957'289 members, which constitutes almost 88% of total number of people, subscribed to these groups. This result shows that in fact the proper support groups are rare. Then 85.8% of

groups have 25 wall posts or fewer, which means that there is not much activity on these groups. Among support groups almost half of it was established by high school or college students and were associated with the greatest number of user-generated contributors. It shows that social networks as a communication tool are still more familiar for young people, even if we could expect that the average age of users of such networks will increase.

Even if, there were only 7% of groups which were mainly established for support purpose, Authors of this paper stress that it “should not be interpreted to imply that Facebook is rarely used for supportive care purpose, given that several ways to solicit or provide support on Facebook were not examined in this study, including private messages, wall posts on personal profile pages, and status updates”.

Thompson L A, Black E, Duff P, Paradise Black N, Saliba H, and Dawson K
Protected Health Information on Social Networking Sites: Ethical and Legal Considerations
J Med Internet Res 2011;13(1):e8

Given that medical professionals are using more and more often social net-

works, the aim of this article was to document and describe online portrayals of potential patient privacy violations in the Facebook profiles of medical students and residents. The authors conducted their study by performing two cross-sectional analyses at the University of Florida in 2007 and 2009 of all medical students and residents to see who had Facebook profiles. Then they manually scanned the entire profiles for any textual or photographic representations of protected health information, such as portrayals of people, names, dates, or descriptions of procedures.

The results of this study revealed that about 44% of all eligible students and residents had Facebook profiles in 2007 and 52.5% had it in 2009. Among them for publicly-available profiles, the authors reported one potential patient's privacy violation in 2007 and 8 in 2009. While for private profiles where only profile page is available, they report zero violations in 2007 and two potentials violations in 2009. In overall it shows that students and residents place protected health information on their publicly available social pages, which raises many ethical and legal related problems.

Lawrentschuk N, Sasges D, Tasevski R, Abouassaly R, Scott A, Davis I D
Oncology Health Information Quality on the Internet - a Multilingual Evaluation
Ann Surg Oncol 2011;19(3):706-13

The purpose of this article is to assess the quality of oncology related information on the web based on the HONcode principles developed by Health On the Net Foundation. In addition authors assess for language or disease differences across four languages: English, French, German, and Spanish.

The proportion of HONcode certified websites found for particular searched term (organ + cancer) oscillates between 11 and 23 %. When analyzing first 50 websites returned by Google they found that the proportion of HONcode certified websites is slightly bigger and is between 15% and 28%, suggesting that HONcode certified websites are considered as viable sources and have better Google ranking.

In conclusion, “a discrepancy exists in quality and number of Web sites across many cancers, and across major Western European languages”.