

Methods to Meet the Informational Demands of Patients and Health Professionals

Findings from the Section on Education and Consumer Informatics

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Summary

Objectives: To summarize current excellent research in the field of education and consumer informatics.

Method: Synopsis of the articles selected for the IMIA Yearbook 2006.

Results: In the consumer informatics field current research focuses on meeting the informational needs of laypersons as well as health professionals with their specific demands and abilities. The selected papers' topics are genetic diseases and conditions, decision support for women considering genetic testing for the risk of breast cancer, history taking and advice for parents with children suffering from asthma, timed messages to motivate and support quit smoking efforts and the integration of health economics in medical education.

Conclusions: The selected articles demonstrate examples of excellent research in consumer health informatics and medical education. The methods presented can contribute to the development of systems for the education of both laypersons and health professionals.

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Keywords

Medical Informatics, International Medical Informatics Association, Yearbook, Education, Consumer Health Informatics

Introduction

Informatics methods have been used for many years in the education of medical professionals, ranging from simple static websites containing educational materials to advanced virtual reality simulations [1, 2]. They are well established as supplementary methods to conventional training.

Medical information in large amounts and different qualities is readily available for laypersons on the World Wide Web. Many research efforts aim at evaluating and ensuring the quality of web sites and their content regarding consumer needs [3-5]. Furthermore applications are designed to address the patients' informational needs concerning specific diseases or conditions – especially for genomics and cancer – in order to empower them to make informed decisions.

Best Paper Selection

The selection of best papers for the section *education* and *consumer informatics* reflects the developments mentioned above. With only one exception – the focus is on education and information of patients rather than medical professionals. This shows the growing impor-

tance of addressing issues of patient empowerment by providing custom-tailored information and support for informed decision making [6, 7].

Table 1 shows the five papers selected from international peer-reviewed journals in the fields of both medical informatics and medicine. They represent examples of excellent research in their respective fields. A brief summary of these papers can be found in the appendix.

Conclusions and Outlook

The selected papers show new trends in consumer health informatics and medical education research. Both the growing knowledge about genomics and its complexity raise uncertainty and concerns in patients who do not understand the potential implications for themselves. This can be counteracted effectively by providing tailored and understandable information about genetic conditions and diseases along with decision support methods [8, 9]. The power of the Internet with its coverage of millions of people can also be used to motivate healthier behaviour [10]. Even if the response rate is low, the sheer amount of persons reached may lead to substantial changes. In [11] the authors demonstrate that, for a specific

Table 1 Selected papers for IMIA Yearbook of Medical Informatics 2006 in the section 'education and consumer informatics'. The articles are listed in alphabetical order of the first author's surname.

Section
Education and Consumer Informatics
<ul style="list-style-type: none"> ▪ Green MJ, Peterson SK, Baker MW, Harper GR, Friedman LC, Rubinstein WS, et al. Effect of a computer-based decision aid on knowledge, perceptions, and intentions about genetic testing for breast cancer susceptibility: a randomized controlled trial. <i>Jama</i> 2004; 292(4): 442-52. ▪ Lenert L, Munoz RF, Perez JE, Bansod A. Automated e-mail messaging as a tool for improving quit rates in an internet smoking cessation intervention. <i>J Am Med Inform Assoc</i> 2004; 11(4): 235-40. ▪ Mitchell JA, Fun J, McCray AT. Design of Genetics Home Reference: a new NLM consumer health resource. <i>J Am Med Inform Assoc</i> 2004; 11(6): 439-47. ▪ Porter SC, Cai Z, Gribbons W, Goldmann DA, Kohane IS. The asthma kiosk: a patient-centered technology for collaborative decision support in the emergency department. <i>J Am Med Inform Assoc</i> 2004; 11(6): 458-67. ▪ Voss JD, Nadkarni MM, Schectman JM. The Clinical Health Economics System Simulation (CHESS): a teaching tool for systems- and practice-based learning. <i>Acad Med</i> 2005; 80(2): 129-34.

disease, namely asthma in children, history taking from the parents as well as patient information can effectively be supported by an interactive system in an emergency department setting.

For a long time health economics has not been integrated into medical education. In [12] the authors present a simulation that can help to fill this gap by conveying the basic principles of health economics and its practical implications to physicians and students.

Up-to-date information about current and future issues of the IMIA Yearbook is available at <http://iig.uit.at/yearbook/>.

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References

1. Lison T, Gunther S, Ogurol Y, Pretschner DP, Wischnesky MB. VISION2003: virtual learning units for medical training and education. *Int J Med Inform* 2004;73(2):165-72.
2. Heng PA, Cheng CY, Wong TT, Xu Y, Chui YP, Chan KM, et al. A virtual-reality training system for knee arthroscopic surgery. *IEEE Trans Inf Technol Biomed* 2004; 8(2): 217-27.
3. Lang JR, Collen A. Evaluating personal health care and health promotion web sites. *Methods Inf Med* 2005; 44(2): 328-33.
4. Soergel D, Tse T, Slaughter L. Helping healthcare consumers understand: an "interpretive layer" for finding and making sense of medical information. *Medinfo* 2004; 11(Pt 2): 931-5.
5. Jadad AR, Delamothe T. What next for electronic communication and health care? *BMJ* 2004; 328(7449): 1143-4.
6. Bott OJ, Ammenwerth E, Brigl B, Knaup P, Lang E, Pilgram R, et al. The challenge of ubiquitous computing in health care: technology, concepts and solutions. Findings from the IMIA Yearbook of Medical Informatics 2005. *Methods Inf Med* 2005; 44(3): 473-9.
7. Knaup P, Ammenwerth E, Brandner R, Brigl B, Fischer G, Garde S, et al. Towards clinical bioinformatics: advancing genomic medicine with informatics methods and tools. *Methods Inf Med* 2004; 43(3): 302-7.
8. Mitchell JA, Fun J, McCray AT. Design of Genetics Home Reference: a new NLM consumer health resource. *J Am Med Inform Assoc* 2004; 11(6): 439-47.
9. Green MJ, Peterson SK, Baker MW, Harper GR, Friedman LC, Rubinstein WS, et al. Effect of a computer-based decision aid on knowledge, perceptions, and intentions about genetic testing for breast cancer susceptibility: a randomized controlled trial. *Jama* 2004; 292(4): 442-52.
10. Lenert L, Munoz RF, Perez JE, Bansod A. Automated e-mail messaging as a tool for improving quit rates in an internet smoking cessation intervention. *J Am Med Inform Assoc* 2004; 11(4): 235-40.
11. Porter SC, Cai Z, Gribbons W, Goldmann DA, Kohane IS. The asthma kiosk: a patient-centered technology for collaborative decision support in the emergency department. *J Am Med Inform Assoc* 2004; 11(6): 458-67.
12. Voss JD, Nadkarni MM, Schectman JM. The Clinical Health Economics System Simulation (CHESS): a teaching tool for systems- and practice-based learning. *Acad Med* 2005; 80(2): 129-34.
13. Lewis SE. Gene Ontology: looking backwards and forwards. *Genome Biol* 2005; 6(1): 103.

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Appendix: Content Summaries of Selected Best Papers, Section Education and Consumer Informatics*

Green MJ, Peterson SK, Baker MW, Harper GR, Friedman LC, Rubinstein WS, et al. Effect of a computer-based decision aid on knowledge, perceptions, and intentions about genetic testing for breast cancer susceptibility: a randomized controlled trial. *JAMA* 2004; 292(4): 442-52

The availability of genetic tests for inherited cancer susceptibility – especially for breast cancer – has greatly increased in the last few years. Hence there is an increasing need for patient education and counseling in order to communicate the knowledge for informed decision making. At the same time counseling resources are sparse, especially in rural areas. Green et al. assess the effects of an interactive computer program on women's education as compared to one-on-one counseling in a randomized controlled trial. They find a significantly higher knowledge increase in the computer-educated group, especially with women with a

* The complete papers can be accessed in the Yearbook's full electronic version, provided that permission has been granted by the copyright holder(s)

low objective risk. However, the authors find personal counseling to be the only effective method to significantly reduce anxiety and to be more effective in reducing decisional conflicts of whether or not to test. They conclude that their program can be used alone to educate women with low risk of hereditary breast cancer, but should be used as a supplement and not as a replacement for counseling, in particular for patients with a high risk of breast cancer.

Lenert L, Munoz RF, Perez JE, Bansod A.

Automated e-mail messaging as a tool for improving quit rates in an internet smoking cessation intervention.

J Am Med Inform Assoc 2004; 11(4): 235-40

Websites containing consumer-adapted medical information are widespread, but often passive in their nature. Lenert et al. use timed email messages with educational and supportive content to assist smokers during their quit efforts, and compare the effectiveness of this approach with that of a website only [10]. The authors measure the number of quit efforts and the length of smoke-free periods. They find significantly more 24-hour quit efforts in the email group (odds ratio 2.6) as well as a higher success rate for seven-day abstinence (13.6% vs. 7.5%). The authors conclude that the use of strategically timed emails raises the rate of short-term quit efforts significantly and – despite low overall response rates – can have a substantial effect because the emails are generated automatically and therefore can easily be used for large population groups.

Mitchell JA, Fun J, McCray AT.

Design of Genetics Home Reference: a new

NLM consumer health resource.

J Am Med Inform Assoc 2004; 11(6): 439-47

Medical knowledge about genetic conditions and diseases increases at a remarkable speed as a result of the Human Genome Project. Laypersons who want to inform themselves about genetic diseases often find it difficult to understand the information presented in genetic databases. Mitchell et al. designed the Genetics Home Reference System which incorporates a data model that represents the multiple relationships between genes and conditions respectively and links them to outside resources using the Gene Ontology [13]. The authors also provide a consumer guide to basic genetic concepts with references to NLM's MEDLINEplus topics. The system initially focuses on conditions and diseases with single gene involvement and is to be expanded to polygenetic conditions in the future.

Porter SC, Cai Z, Gribbons W, Goldmann DA, Kohane IS.

The asthma kiosk: a patient-centered technology for collaborative decision support in the emergency department.

J Am Med Inform Assoc 2004; 11(6): 458-67

Detailed information about a patient's history is – along with a good physical examination – the basis for a good diagnosis and appropriate treatment. Porter et al. introduce a system – the Asthma Kiosk – that collects information from parents of asthmatic children in an emergency department setting [11]. They use a mobile system with a graphical user interface and a touch-screen display. The users are guided through a number of questions concerning symptoms of asthma, medication details and other relevant data. Fi-

nally a report is created along with guideline-based recommendations for both doctors and parents.

The authors evaluate their system (n=14-65) by measuring the time spent on data collection (11 minutes) and by semi-structured interviews for parents' evaluation of the system as well as their comprehension and reactions to the output. They conclude that the Asthma Kiosk effectively connects parents' data with guideline recommendations and is able to document data (e.g. environmental triggers) which are critical for asthma management and improvement and which can easily be overlooked in an emergency setting.

Voss JD, Nadkarni MM, Schectman JM.

The Clinical Health Economics System Simulation (CHESS): a teaching tool for systems- and practice-based learning.

Acad Med 2005; 80(2): 129-34

The last selected article covers an area of medical education that is often neglected, health economics. Voss et al. present CHESS, a simulation tool that allows students and resident physicians to view the impact of their healthcare decisions on physician's income, patient's costs and societal costs in different scenarios [12]. Simulation and scenario variables can be changed, and learners are organized in teams each representing a physician practice.

The authors evaluate their system (n=68) and find that 97% of the participants prefer CHESS to a conventional lecture and discussion teaching approach. They conclude that their system offers an effective method of teaching the principles and practice of health economics.