Consumer Health Informatics (Updated July 2013)

Chair (2011-2014)
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Scope

The Consumer Health Informatics Working Group (CHIWG) became an official IMIA Working Group in 2000. The CHIWG is concerned with electronic information related to health care available to the public (e.g. Internet, wireless, standalone electronic media). For its purposes, it defines Consumer Health Informatics as “the use of modern computers and telecommunications to support consumers in obtaining information, analyzing unique health care needs and helping them make decisions about their own health” (U.S. General Accounting Office, 1996, p.1.), in which the consumer interacts with the applications with or without the presence of health care professionals. The group's interests focus on, but are not limited to, world wide web sites that offer advice about healthy living, research findings, and recommendations on specific disease conditions, descriptions of products, medications, and self-care health programs available to the public. Issues of concern may be the evaluation of the quality of information, education of the public, ethical issues related to the electronic information, and the effect on a person's health care and relationship with health care providers.

Objectives for the next 3 years

The WG hopes to work with the IMIA leadership on strengthening the role of the Working Groups within IMIA. We look forward to greater participation in key IMIA activities, increasing the visibility and impact of CHI WGs in the world. Provide greater opportunities to share CHI related information from relevant and accessible sources such as the International Journal of Medical Informatics (IJMIA), and the Journal of Medical Internet Research (JMIR). Emphasis will be given to high-quality studies and randomized trials published in quality journals. The group plans to hold a business meeting at Medinfo, and plans a tutorial. The group will continue to liaise with counterparts in other countries, such as the AMIA WG CHI, EFMI, IMIA's NI-SIG(WG on CHI). A priority will be to expand our contacts with CHI interest groups in Asia and Africa.

Recent Activities

Public relations

AMIA 2013 fall conference panel: “Ethical, legal, and public policy barriers to unleashing the full power of Consumer Health Informatics for care delivery”. Few successful Consumer Health Informatics services make it from research into practice, partially because it is illegal to practice medicine without any face-to-face contact and because national legislation prohibits utilization across state, let alone national borders although the character of a service would allow so. With a psychiatrist, nurse and two lawyers I will explore whether services are safe and mature enough for an ethical urge to advance legislation.
Textbook: “Consumer Health Informatics – new services, roles and responsibilities” to appear with Springer scientific publisher in 2014. We have the books by Slack, Cybermedicine, 2001, by Nelson and Ball, Consumer informatics, 2003 and more specialized ones such as Bauer’s and Kordy’s E Mental – Health 2008. But there is no systematic account of such aspects as user rights and responsibilities, of national economics need and impact, of clinical trial methodology for comprehensive services etc. Besides major parts by myself the book will contain specialist chapters on confidentiality, smart environments, and swarm intelligence.

Membership, leadership

My attempts to ground the working group with colleagues from Third World countries taking active roles is behind schedule. I am in contact with more young researchers in Africa, Asia and South America. However the persons I have identified believe it is too early for them to take a leadership role. I dearly hope that one or two of them will be ready in a year from now.

**Future Activities**

Activity to promote broader representation in 3rd world countries where the effort - effect ratio can be enormous. Concrete actions might then emerge upon request of newly engaging countries.

Activity to promote getting another MeSH keyword, to allowed focused search for all those we try to get on board.