Patient Libraries and information Services in Italy

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Summary
"In the developed world, about 39% of persons with cancer are using the Internet, and approximately 2.3 million persons living with cancer worldwide are online. In addition, 15% to 20% of persons with cancer use the Internet indirectly through family and friends." (1) Unfortunately, the Internet cannot guarantee the quality of information. Library and information services for patients play a crucial role for spreading good information tailored to patient needs, also considering that large part of the population (in Europe 60-65%)do not have access to the Internet or are unable to obtain online information from the Web.

Two national projects: SICOP (Information System for Oncological Communication with Patients) and SIRIO (Individualized Service of Request of Information in Oncology) were granted by the Italian Health Minister, between 2007-2008, in order to develop shared methods and highly qualified patterns for the management of the oncological libraries and Information
services. All the libraries and information services, active in the Italian Comprehensive Cancer Research Centres, participate in the projects acting as a network. These Projects rely on the work of multidisciplinary teams: librarians, psychologists, clinicians , nurses and volunteers who cooperate within research centres, hospitals, advocacy groups and patient associations. The SICOP Project produced a pamphlet titled "Quando un sito è ok!"(When a site is ok), a guide for patients and laypeople, regarding quality health websites, partially granted also by MIUR (Italian
Ministry of University and Research). A census of about 80 libraries (scientific and recreational) and Information centers for patients in Italy was also developed.

SICOP and SIRIO worked together in order to build a shared patient database with the aim of producing standardized statistical data about the users' features and their information needs. Other common activities was the creation of an educational pattern, focusing on basic knowledge of psychology and library science, for both the staff and the volunteers of patient libraries. Furthermore a unique brochure was designed and is currently being used with the aim of promoting the information activities for patients in all the centers involved in the projects. Last but not least,SIRIO and SICOP staff are implementing an user satisfaction questionnaire to receive feedback from patients and their relatives. Cignoweb, the Italian database of information resources in oncology and allied sciences for patients and citizens, an Alliance Against Cancer Project, produced by CRO will be soon available too.

Other libraries can take advantage of the shared tools already made available by SICOP and SIRIO, to ensure that quality health information can reach the general public wherever they live or work throughout the country, widening oncologic information

systems to other sectors of interest for patients. Thus it will promote the patient empowerment, putting laypeople in charge of their own health choices. Patient empowerment is our challenge within a patient centered health system.

(1) G. Eysenbach. CA A Cancer Journal for Clinicians. 2003: 53(6)