Azalea:
an innovative system for evaluating the quality of information for patients

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The multicenter project Azalea, an oncological digital library for patients, their relatives and the public, began in 2002, with a grant from the Alliance Against Cancer (AAC), a network of seven Italian national cancer research institutes.

The Azalea database - accessible via www.azaleaweb.it - currently contains approximately 3000 documents in print and electronic format, including some 1400 records of cancer patient associations. The majority of the documents catalogued in Azalea comprise "grey literature" and electronic resources held on Web sites. This requires that close attention be paid to quality evaluation and to psychological impact, in addition to the appropriateness of the information and readability (patients "are not empty buckets into which bits of data, treated like bricks, can be tossed"./L. Bunyan). The evaluation of the quality of information for patients is of particular importance, considering the ethical problems inherent in incorrect and non-validated information being widespread in the health sector. Such problems take on an even more alarming aspect where the Internet is concerned.

In order to ascertain the quality of the information which can be accessed through the database, Azalea has developed an original method of evaluation to apply not only to electronic resources (web sites etc.) but also to paper-based documents - many of these latter being, as already stated, informal grey literature often produced by small patient associations. The evaluation procedure is complex even though it has been simplified as far as possible, and requires the input of multidisciplinary teams.

The initial phase of evaluation involves the document being assessed by a cataloguer in terms of its technical-formal aspects. One may call this first step the "Librarians' Evaluation". The Librarian evaluates the document by means of grids designed on the basis of internationally accepted criteria (transparency, appropriateness, authority, currency and date, interactivity, accessibility and usability standards and conduct criteria)

The second step is the "Communication Evaluation" , performed by a team with expertise in the field of communication (psychologists and librarians). They provide a detailed assessment of the readability (comprehensibility) and psychological impact (relativity and emotional impact) of the documents by means of a specific evaluation grid.

The third step is the Scientific Evaluation. A medical committee examines every document and evaluates its scientific content (validity, precautions usefulness) by means of a purpose-built grid.

Last but not least is the patients' evaluation which rates the user satisfaction.

The evaluation process is therefore conducted by means of three different grids, originally drawn up on the basis of the experience of international organizations which have studied and produced guidelines for the evaluation of healthcare web sites (HonCode, EU Criteria, Discern,

Quick etc.). Each evaluator or group of evaluators assigns a score with a scale of 1 to 5 as in the Likert scale (Discern model) for each criterion in the grid. The evaluator is required to write a brief summary (no more than three lines) in which the strong and weak points of the document are highlighted .The evaluator is also required to indicate whether the document is appropriate for first level information (general public) or second level (more expert public)

At the end of this process the professional librarian writes a final short summary, which is added to complete the document record in Azalea

The patient can directly read the evaluation of the document in Azalea.

The Centro di Riferimento Oncologico di Aviano has designed a questionnaire to be administered to patients in order to gain additional information (patient's evaluation) Patients were required to fill out a user satisfaction questionnaires to evaluate the delivered documents From a survey - which is still ongoing - on the basis of 84 questionnaires returned, it emerges that 98% of patients or family members believe the documents contained in the database to be, to varying degrees, sufficiently comprehensible, clear, complete and useful. The whole process enables continuous feedback between providers and users of health-related content. One may represent it as an evaluation circle that involves on the one side specialised librarians, psychologists, oncologists, and patients who rate the content of the documents and on the other side the information providers. Once the patient documentation has been evaluated it may be sent back to its producers (associations, scientific societies, commercial publishers, individual authors) in order that they may take appropriate steps to improve it..

Some associations, are also undertaking quality evaluation of documents prior to making them available on their site.

This process is undoubtedly useful in order to improve the quality of Italian patient literature output, and thereby avoid the risks inherent in disseminating non-validated information in the health care sector.

In order that patients may be pointed in the direction of high-quality resources, the Azalea project also provides for the establishment of a network of libraries to assist the patient in his or her quest for information, thereby guaranteeing a tailor-made response.

Azalea is, therefore, a product that brings together highly technical factors - state of the art informatics, international standards of cataloguing and information exchange - with those more centered in the interpersonal arena - the ability to listen and empathise with the person who desperately needs information about their illness, and collaboration with voluntary associations. The overall aim is to provide the user with a solid and reliable point of reference and orientation in the sphere of cancer information.

A brief bibliography
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