Abstract

Objective: the objectives of this article are: (a) to provide an analysis of the key factors of an efficient web strategy with regard to the issue of patient empowerment, (b) to build an index for measuring the degree of empowerment of healthcare providers’ web sites, (c) to measure the degree of “patient web empowerment” within the Italian National Health Service (INHS).

Methods: a Patient Web Empowerment Index (PWEI) was built, through aggregation and weighting of 8 sub-indicators.

Results: PWEI was calculated in order to assess yearly (since 2009 to 2011) the web sites of 340 INHS healthcare organizations, the aim being the appraisal of the current degree of maturity of their web strategies for an effective increase in patient empowerment.

Conclusions: the web strategies of health organizations basically reflect a state of deep immaturity and they still display a tendency to modulate their approach with the accent all too frequently placed on the structures and responsibilities of the organisation itself, rather than on the needs of citizens-patients.

Practical implication: PWEI could play a role in order to benchmark, also at international level, the web strategies of health organizations and could therefore support a patient-centered web design of information and services.

1. Introduction

Internet revolution has deeply impacted relations on every context of exchange of goods and services. We may definitely agree that, since last decade, the major impacts of these transformations on relations between ‘suppliers’ and ‘customers’ on markets consist in [1]:

a) low-cost availability (or availability even free of charge) to the customer of considerable amounts of information useful for purchasing decision-making;

b) a consequent increase in the degree of transparency of markets;

c) a significant enhancement of the empowerment of citizens/customers in many real life situations and in relations with various (public or private) suppliers.

Nowadays, citizens are aware of this historic change that is taking place and they are the bearers of a growing demand for a wide scale adoption of web channels, also within contexts such as healthcare services use [2], where, traditionally, exchanges of information between patient and care provider are significantly ‘asymmetric’ and “formal” as for their nature.

Patient empowerment, markedly tied in with the spread of the Internet and of technological resources as a part of our day-to-day lives (in which the Internet is now ‘embedded’), represents one of the major challenges that healthcare systems face today [3-5]. Statistical data regarding the use of the leading search engines indicate that questions concerning “health” are among the most frequently occurring [6, 7]. However, patients face difficulties when searching the Internet for health-related information, because of information overload and contradictory or complex information [8].

More broadly speaking, patients are nowadays the bearers of new demand, which we may summarise as follows:

a) access to authoritative, customized and immediately usable health information [9];
b) greater control over their own personal conditions of health, through personal management of pertaining data, and over the various diagnostic and therapeutic options available [10-12];
c) direct and informal relationships with healthcare structures and professionals, also via non-traditional channels [13, 14];
d) role as ‘active player’ within the network, also by sharing their own health problems with others [15-17] and seeking out information on the experiences of others faced with these same problems; web 2.0 logic [18, 19] has considerably amplified this latter development.

In equal measure, in the scientific literature and strategic decision-making processes in the field of healthcare provision systems, the concept of “patient empowerment” therefore constitutes an increasingly significant issue, which is the focus of interest and debate among academics and policy makers alike [4, 20-24]. Within the field of healthcare provision, the concept of empowerment has been adopted on various levels [25]: on the macro level, analysis takes place of the relationship between health and power. A number of studies suggest that empowered people are healthier than non-empowered people; lack of power is therefore a disease risk factor (dependent upon structural factors) [26, 27]. On the micro or individual level, the concept of empowerment has been used to define a particular type of patient. It is here that we arrive at the notion of patient empowerment:

“Patients are empowered when they have the knowledge, skills, attitudes and self-awareness necessary to influence their own behaviour and that of others (…) to improve the quality of their lives.” [28]

It is presumed [29] that the final objective of patient empowerment is that of obtaining a higher degree of compliance on the part of the patient:

“Patient empowerment is therefore most often defined as a process of behaviour change, with a focus on how to help patients become more knowledgeable and take control over their bodies, disease and treatment. In this definition, empowerment is viewed as a process of “activating” patients, who as a result of “rejecting the passivity of sick role behaviour and assuming responsibility for their care (…) are more knowledgeable about, satisfied with, and committed to their treatment regimen” [30].

A recurring issue is the balance of roles and responsibilities between the patient and the health provider. For instance, using the Internet to seek health information raises the issue of the threshold of competencies required for an individual to make quality decisions on health and act appropriately, as well as the uncertainty on the degree of control that an individual can in fact achieve over health problems [6].

In the presence of challenges such as these, we nevertheless note that the adequacy and characteristics of the web strategies of healthcare providers have, up to the present, not been subjected to thoroughgoing critical analysis [31].

2. Objectives and methods

The aims of this paper are:

a) to provide an analysis of the key factors of an efficient web strategy with regard to the issue of patient empowerment;
b) to build an index for measuring the degree of empowerment of healthcare providers’ web sites according with their service and information strategy;
c) to measure the degree of “patient web empowerment” within the Italian National Health Service (INHS)

The research project described here aims to engage in a more in-depth study of, and to elaborate upon, the issue of patient empowerment within the context of the introduction of information and communication technologies (ICT). A study has been conducted of the healthcare applications of these technologies, classified according to their impact on the two key dimensions of patient empowerment: information held by the patient and control on the part of the patient with respect to his/her health needs. The baseline research hypothesis is that the information and services provided by Health providers via the web are capable of enhancing patient empowerment regarding both the above mentioned dimensions.

The basic question this research addresses may be summed up as follows: “To what extent are the web strategies of IHNS organizations aimed at increasing patient empowerment?”. The following steps were followed:

a) A systematic literature review was performed, aimed to understand the main items of the web strategy in term of contribution to patient empowerment. Databases and citation indexes, such as Web of Science and PubMed, were used as well as specific journals were searched. Next, the titles and the abstracts of the identified articles were checked for eligibility and
relevance and were classified in homogenous items categories.

b) According with the above mentioned categories, the authors have developed a succinct indicator, termed Patient Web Empowerment Index (PWEI), that is the result of aggregation and weighting of 8 sub-indicators, each of which is calculated on the basis of the presence of certain elements characterizing the structure of the web site considered.

c) The indicator was developed in 2009 and was later used to assess yearly (2009, 2010 and 2011) the web sites of the entire universe of public (and private contracted) INHS healthcare organizations (340 LHUs’ and HTs’ sites were benchmarked), the aim being the assessments of the current state of maturity of their web strategy in relation to potentials for an increase in patient empowerment. During the stage of quantitative determination, the value 1 was ascribed to the presence of the service or of the information considered, value 0 to absence, and value 0.5 to incompletely structured presence.

Analysis and rating of sites were based on two fundamental criteria:

a) the immediacy in finding information or services while navigating the site (“hidden” services were not considered if time-consuming procedures were necessary in order to find them);

b) the official and systematic (as opposed to sporadic or “pilot only”) presence of the information or services in the examined web sites.

The evaluation task is randomly assigned to three coders (the authors). The intercoder reliability of each PWEI subindicator is tested yearly on a 35-sites subset using the Krippendorff’s alpha coefficient [32]. Overall, use of PWEI rating system was found to be highly reliable as shown in table 1, which also shows a progressive increase of the reliability.

Table 1 Intercoder reliability (Krippendorff's alpha values for the subindicators, yearly subset n=35)

<table>
<thead>
<tr>
<th>PWEI Subindicator</th>
<th>α 2009</th>
<th>α 2010</th>
<th>α 2011</th>
</tr>
</thead>
<tbody>
<tr>
<td>PWEI Site</td>
<td>0.8267</td>
<td>0.8933</td>
<td>0.8002</td>
</tr>
<tr>
<td>PWEI Clinic</td>
<td>0.8802</td>
<td>0.9299</td>
<td>0.9782</td>
</tr>
<tr>
<td>PWEI Community</td>
<td>0.8525</td>
<td>0.8597</td>
<td>0.9654</td>
</tr>
<tr>
<td>PWEI MD2P</td>
<td>0.84</td>
<td>0.8849</td>
<td>0.9435</td>
</tr>
<tr>
<td>PWEI PHR</td>
<td>0.8202</td>
<td>0.8963</td>
<td>0.9165</td>
</tr>
<tr>
<td>PWEI Choice</td>
<td>0.7571</td>
<td>0.8776</td>
<td>0.8533</td>
</tr>
<tr>
<td>PWEI Telemed</td>
<td>0.8856</td>
<td>0.9041</td>
<td>0.8256</td>
</tr>
<tr>
<td>PWEI Innovation</td>
<td>0.9976</td>
<td>0.9775</td>
<td>0.9654</td>
</tr>
</tbody>
</table>

3. PWEI index

PWEI, as pointed out above, is a multidimensional indicator, composed of a series of sub-indicators whose objective is measurement of the various aspects of patient empowerment via the web. The typologies of information and services that users can find on the sites of Italian health organizations, in fact, vary greatly. Thus, the capacities of these health organizations to contribute to user empowerment also vary – empowerment ranging from access to knowledge, to control of data concerning ones personal conditions of health via the electronic medical record and telemedicine.

As we explained above, the sub-indicators were defines according with the results of the literature review performed. Table 2 summarizes the most relevant scientific sources used to define the sub-indicators.

Table 2 Main scientific sources used to define the sub-indicators

<table>
<thead>
<tr>
<th>PWEI Sub-indicator</th>
<th>Source(s)</th>
</tr>
</thead>
<tbody>
<tr>
<td>PWEI Site</td>
<td>[33]</td>
</tr>
<tr>
<td>PWEI Clinic</td>
<td>[34] [35] [36] [37]</td>
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<tr>
<td>PWEI Community</td>
<td>[38] [39] [40] [41] [42] [43]</td>
</tr>
<tr>
<td>PWEI MD2P</td>
<td>[34] [44] [45] [46] [47] [48] [49]</td>
</tr>
<tr>
<td>PWEI PHR</td>
<td>[50] [51] [52]</td>
</tr>
<tr>
<td>PWEI Choice</td>
<td>[53]</td>
</tr>
<tr>
<td>PWEI Telemed</td>
<td>[54] [55] [56] [57]</td>
</tr>
<tr>
<td>PWEI Innovation</td>
<td>[58]</td>
</tr>
</tbody>
</table>
The first element making up the overall index of patient empowerment has been termed **PWEI Site (P1)**. It relates to certain structural characteristics of the site which enable user-friendly navigation and which, above all, respond efficiently to the primary information needs of the patient. Assessment was conducted on a number of these characteristics:

- a) accessibility (e.g. the option of graphics changes, including font size, for patients with eyesight problems, or to facilitate handheld computer or mobile phone site access) and immediate usability of the content and services provided by the examined healthcare provider;
- b) site structure, including rating of sites enabling the “life events model” for navigation (i.e. navigation starting out from events which may characterise the life, in health terms, of the patient, such as “giving birth”, “growing” or “life as a senior citizen”), or which provide clear segmentation of patients by cluster (the elderly, women, children, foreigners etc.): web sites designed according to these approaches may aid consultation by patients presenting specific problems, who thus receive immediate answers targeting their specific needs;
- c) guide of the health organization aimed to support and orient the patients among the services provided: clear presentation of the organisational structure of the health unit was therefore also assessed.

The second component of the indicator consists in the clinical information that may be obtained by patients from the site. To construct sub-indicator **PWEI Clinic (P2)**, various elements relative to health information present on the site were considered, ranging from simple leaflets or fact files to tests for assessment of the clinical risks of individuals or information for self-diagnosis. Investigation was conducted on the presence of the following categories of downloadable items:

- a) leaflets or fact files on specific pathological states;
- b) leaflets dealing with prevention and for promoting correct lifestyles;
- c) guides aimed to allow a better self-understanding of lab examinations results;
- d) healthcare provider’s magazines or newsletters with information regarding health and healthcare issues;
- e) guides for self-diagnosis;
- f) questionnaires and clinical risk assessment tests.

Use of each of the first four elements can generally be enabled by file downloading or – in rare instances – by video, links to internal resources (web pages maintained by professionals from the health unit) or links to external resources (the resources of the Health Ministry, the sites of Regional government authorities or regional health agencies, on-line libraries).

The third component of the indicator is termed **PWEI Community (P3)**. This sub-indicator assesses the presence of on-line communities or groups which provide information, psychological support or care to patients with special health problems. The following entities were noted:

- a) web institutional communities: counseling; on-line support centres (e.g. stop-smoking, dietary health problems, etc.);
- b) bookmarks for web support group resources, i.e. direct links to medical sites or sites run by voluntary players or by patients;
- c) lists of, and references to, non-web community and support group resources (generally, address directory mode).

A further sub-indicator – contributing to significant enhancement of the quality and quantity of clinical information available to users – consists in direct on-line medical doctor-patient communication (**PWEI MD2P – Medical Doctor To Patient – P4**): patients can directly contact professionals for health information or advice. In this context, the prospect of adoption of a multi-channel approach on the part of health organizations was also considered (telephony or digital terrestrial television communication resources, alongside the Internet). Thus, the systematic presence of the following elements was assessed:

- a) evidence of a telephone channel for generic health advice and information;
- b) evidence of a telephone channel for health counseling on specific issues (e.g. influenza, contraception, AIDS, etc.);
- c) evidence of use of email communication on the part of health professionals;
- d) moderated institutional forums primarily for patients;
- e) blogs, forums or live sessions for communication between patients and medical doctors;
- f) FAQ service on health issues providing health professionals’ answers to users’ questions.

A further key aspect considered for an assessment of empowerment consists in access to ones own **Personal Health Record (PHR – P5)**, generally
understood as an electronic format record with information on the health conditions of the individual, alongside a record providing the full medical history of the person in question, directly accessible via web. PHR is therefore an important instrument in terms both of information and control of one’s own personal health data. Sub-indicator PWEI PHR evaluates the opportunity for the patient to examine and download his own PHR, directly from the health organization’s web site or by other means (e.g. via electronic card or through the intermediation of primary care professionals or other actors).

The expectations of many users have grown, and these users display greater awareness of the importance of selecting professionals and the most appropriate structure (safety, specialization, available technologies and methods, etc.) for healthcare provision and optimal responses to their health problems. This aspect was processed by means of a further component of the index, i.e. PWEI Choice (P6). This sub-indicator accounts for a number of the most important elements which, if present on the site, may provide patients with orientation in selecting the most appropriate health unit and professionals for the required service. These elements, in any case, are auspicious in terms of transparency of health unit during dealings with users, namely by provision of user-friendly access to:

a) Health professionals’ curriculum vitae data
b) information on the typology and quantity of treated cases by pathological condition;

c) waiting lists for diagnostic services, specialist examinations and emergency room admissions.

The need to meet increasingly complex demands determines the need to re-configure the processes of health care delivery, this latter aim receiving a significant stimulus from progress in the ICT field. In this context we note the potentials of telemedicine, which generally enables virtual mode clinical diagnosis without physical contact between patient and medical doctor. For the purposes of analysis, a search was made for unequivocal provision of the following services on the sites of health units:

a) specialist tele-counseling;
b) telehomecare;
c) emergency telecare.

Assessments relative to these elements were pooled in sub-indicator PWEI Telemed (P7). The availability of services provided by telemedicine system enables greater control by the user of personal conditions of health.

Lastly – for individual cases – the presence on sites of certain ancillary ICT-based services was surveyed, such as webcam or photo albums for newborns (provided by maternity departments or by intensive treatment departments). These innovations were translated into the last sub indicator: PWEI Innovation (P8), gauging the presence of particular innovations (including innovations which are exceptional in nature and which go beyond the impacts, in terms of information and control, investigated during the research under discussion here).

Each of the above mentioned sub-indicators, determined on the basis of scientific literature on patient empowerment, was weighted according with its significance for the enhancement of patient empowerment. In our case study, the weights for the eight sub-indicators derived from a pilot survey carried out across informed interviewees at the authors’ institutes, using the participatory budget allocation approach [59, 60].

Equation (1) shows how the total PWEI value is calculated by weighting the 8 sub-indicators. The maximum theoretical value of the PWEI is 10.

\[
PWEI = 0.5 \text{P1} + 2 \text{P2} + 0.5 \text{P3} + 1.5 \text{P4} + 2 \text{P5} + 2 \text{P6} + 1 \text{P7} + 0.5 \text{P8}
\]

4. PWEI values in Italian hospitals

From analysis of the Patient Web Empowerment Index indicators we learn that, as yet, few Italian health organizations have developed web-based strategies oriented toward information and users’ control of clinical data. Although, nationally speaking, the presence of best practices was noted (above all, in Lombardia and Emilia Romagna regions), it was observed that none of the local health units surveyed had reached an overall PWEI rating approaching the maximum theoretical value of 10.

The overall PWEI results for Italy are shown in Table 3. They can also be assessed by geographic area: the health units of Northeastern and Northwestern Italy rated higher than the national average. The data reveal a nationwide gap situation with regard to patient empowerment via web sites. While Northern Italy’s average PWEI values were not particularly high, this area does seem to be gradually coming round to the idea of paying more attention to web strategies targeting the users of its health units. The health units of the Regions of Central and Southern Italy, despite an improving trend, still display an
inability to implement the services provided by the web for responding to patient needs.

Table 3. Average PWEI values for Italy (n=340 websites (min 0 – max 10)

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<th>2009</th>
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<th>2011</th>
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<tbody>
<tr>
<td>PWEI Site</td>
<td>1.50</td>
<td>2.19</td>
<td>2.87</td>
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Particularly worthy of note is the prospect of PWEI sub-indicators analysis. The average national values for PWEI sub-indicators in 2009, 2010 and 2011 are listed in Table 4 (in a 0-10 scale).

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Data show the greater significance of the PWEI Site, PWEI Community and PWEI PHR sub-indicators. For PWEI Site, the value is directly ascribable to the almost universal existence at least of an institutional web site. For PWEI Community and PWEI PHR, the result is owing to the positive outcomes noted in a number of the major health organizations. A comparison between 2009 and 2011 show a small but significant increase of the values of all the sub indicators, with the remarkable exception of the value of the PWEI Telemed, which decreases. This trend is related with the closure of several telemedicine pilot-projects, after a prototypal phase.

Table 4. National average values for each PWEI sub-indicator (min 0 – max 10)

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5. Discussion and conclusions

The analysis offered a number of interesting results regarding each of the surveyed ambits and a number of best practices, where these could be found.

With regard to the PWEI Site component, research revealed that very few health organizations had enabled a system for web site use of information based on a “life event” approach. Other health providers selected visitor-type clusters (e.g. the elderly, special-needs patients, foreigners, etc.) as a means of orienting information users. While taken up by a greater number of health organizations (compared to the life event system), this latter option remains infrequent within the entire surveyed sample. Indeed, this was the choice made by most health organizations in Emilia Romagna Region and by a considerable number of organizations in Lombardia Region. In the other Regions, however, this type of segmentation of visitors was sporadic, the menus bring based instead on the organisational structure of the concern (e.g. districts, departments, hospitals etc.).

Analysis of PWEI Clinic elements revealed that there are practically no guided support resources for self-diagnosis or assessment of personal clinical risks (the two exceptions regard diagnosis of cardiovascular and melanoma risks). The LHU generally provide downloadable leaflets dealing with prevention, above all for tumour screening and for promoting healthful lifestyles. Information files on specific pathological states are more frequently to be found on the sites of HT than on those of LHU concerns.

Turning to communities aspects (PWEI Community), only a few health organizations host institutional support groups (in most cases, voluntary associations for specific patient types). Sites hosting bookmarks or lists of pertaining associations are more frequently found. This information was systematically included in the sites of the health organizations of specific regions.

In terms of medical doctor-patient relations (PWEI MD2P), few health organizations have, as yet, made provisions for an interactive approach to exchanges between the two players. Indeed, there are few telephone lines for patient orientation on health concerns, both with regard to general services and specific areas of specialisation. On their sites, the health units of Emilia Romagna refer to a dedicated AIDS telephone line (Helpaids): the project was actually started up by the Regional authority, and not by LHU. Generally speaking, health professionals’ personal email addresses are not hosted by sites, with some exceptions (while cases are to be found, this service does not generally regard all medical staff in the organisation). Only on some sites are user-accessible forums and blogs to be found. Managed by counseling centres, they target adolescents and women. Solutions enabling medical doctors to respond to user questions via the FAQ function are slightly more frequently to be found.

For Personal Health Record (PWEI PHR), we must distinguish between two differing operational ambit: a) single health organizations which independently decide to develop systems for citizens’ personal health records;
b) PHR systems implemented within the ambit of regional projects.
In the former case, there are, as yet, few health organizations which have made provisions for such instruments. Only Lombardia and Emilia Romagna regions have so far developed regional IT projects for electronic health record management. The CRS-SISS (Regional smartcard for access to health data and public services) project of the Lombardia regional authority aims to plan, develop and manage the information system enabling telematic links in the region. The SOLE (Sanità On-line) project consists in a computer network with links between 3,800 general practitioners and paediatricians and all the medical structures and specialists of the health units of the Emilia Romagna region. These regional projects were considered when assessing the sites for the health organizations of these two regions, and the presence of PHR was duly taken note of, although at present the projects have not been fully implemented in terms of the prospect of direct PHR use on the part of patients [12, 61].

Performance for telemedicine applications (PWEI Telemed) is still unimpressive. A number of LHU, especially in some Northern regions, do have pilot projects, ranging from emergency telecare for infarcted patients to telehomecare for the elderly, but there are only a few services provided on a regular basis.

With regard to PWEI Choice, we note that, with the exception of certain organizations, the sites do not systematically include curriculum vitae data for their professionals and there is practically no information at all on case-mix treated by health organizations or professionals. Hospital managers’ CV publication is foreseen by law at a national level as an administrative pro-transparency measure; real-time waiting lists data are available only on approximately fifty sites.

A number of preliminary conclusions may be reached on the basis of this study. Three general points may be considered:

- health organizations’ awareness of the potential role of web instruments for curbing ‘asymmetric information’ situations between medical doctor and patient is only partial. Indeed, only a few web resources have been made available such as provide solutions capable of responding to a broad range of health needs displayed by the citizens;

- we find considerable resistance to the idea of using the web as a means of truly and significantly enhancing transparency, this aim being frustrated to a considerable extent. This situation is evident for all areas and all ‘critical’ services, i.e. “real time views” (of waiting lists) or on-line CVs of professionals. While we are aware that the degree of cultural resistance to such innovations is significant, we believe that this ambit may represent a natural and interesting track of development of web strategies;

- the web strategies of Italian health organizations basically reflect a state of immaturity and they still display a tendency to modulate their approach with the accent all too frequently placed on the structures and responsibilities of the organisation itself, rather than on the needs and demands of citizens-patients. While the site design, both from the graphics angle and the information content, seems to be well executed and satisfactorily updated, the logic behind is still based on its own institutional and organizational aspects although patients may not be familiar with such organisational aspects. By adopting this approach, transparency may be impeded with respect to specific needs.

Overcoming the three above mentioned limits may turn out to be a prerequisite for concrete development of “healthcare 2.0” – a concept for innovation which healthcare systems are beginning to discuss.

Finally, the study highlights also some limits, which deserve further analysis and can be summarized as follows:

- a user-satisfaction analysis (personnel and patients) has not been undertaken; this would significantly enrich the ability to evaluate the significance of the indicator and the weights of the sub-indicators;

- the analyzed experiences are still characterized by a significant “pioneering” innovation and this feature limits the possibility to generalize the results obtained.

In our opinion, the developments of PWEI index could play a role in order to understand, benchmark and monitor, also at international level in future studies, the web strategies of health organizations and it could therefore support a patient-centered web design of information and services. A widespread adoption of this tool could contribute to a faster development of authoritative web solutions aimed to patient empowerment, supporting both the patient and the caregivers in developing trust and partnership relationships, that is essential to develop quality and value for money.

Benchmarking means improvement can be measured and when improvement is reported it increases exponentially. PWEI index measures healthcare performance from the citizen’s (customer)
perspective rather than an healthcare organization’s point of view. For too long now, this perspective has been missing.

6. References


