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Patient web empowerment index (PWEI): An index for assessment of healthcare providers'web strategies. Case study: PWEI application in Italy

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Abstract

The arrival of the Internet contributes to the growth of new areas for patient empowerment. In the presence of a challenge such as this, 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. The aim of this paper is to: (a) provide an analysis of the key factors of an efficient web strategy for healthcare organizations with regard to the issue of patient empowerment (b) build a concise indicator for measuring the degree of empowerment potential of healthcare providers' web sites (Patient Web Empowerment Index –PWEI-). PWEI was calculated in order to assess the web sites of 340 Italian National Health Service healthcare organizations, the aim being the appraisal of the current degree of maturity of their web strategies in relation to potentials for an effective increase in patient empowerment

Keyword:

Patient advocacy, Patient participation, Health promotion, Internet, Medical records, Telemedicine, Social marketing, Italy

Introduction

The arrival of the Internet has deeply impacted relations in terms of the exchange of goods and services in innumerable contexts. We may note that the major impacts of these transformations on relations between 'suppliers' and 'customers' consist in: (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 and are bearers of a growing demand for the adoption of web services, also within contexts such as healthcare, in which, traditionally, exchanges of information between patient and care provider are significantly 'asymmetric'and formal. 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 healthcare systems face today. Statistical data regarding the use of the leading search engines indicate that questions concerning "health" are decidedly among the most frequently occurring. More broadly speaking, patients are nowadays the bearers also of new demands or desiderata, which we may summarise as follows: (a) access to authoritative, customized and immediately usable health information; (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; (c) direct and informal relationships with healthcare structures and professionals, also via non-traditional channels; (d) role as 'active player' within the network, also by sharing ones health problems with others and seeking out information on the experiences of others faced with these same problems (web 2.0 rules, the basis of social networks, 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 variable, which is the focus of interest and debate among academics and policy makers alike [1-3]. Within the field of healthcare provision, the concept of empowerment has been adopted on various levels [4]: 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) [5]. 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 [6]."*

In the presence of a challenge such as this, 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. The aim of this paper is to: (a) provide an analysis of the key factors of an efficient web strategy for healthcare organizations with regard to the issue of patient empowerment (b) build a concise indicator for measuring the degree of empowerment potential of healthcare providers' web sites (c) measure the degree of patient web empowerment within the Italian National Health Service (INHS).

Methods

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 various typologies of web information and services were used to develop a succinct indicator by means of which ratings could be given for the web sites of Italian Local Healthcare Units (LHU) and Hospital Trusts (HT). This indicator, termed Patient Web Empowerment Index (PWEI), 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 characterising the structure of the web site considered[1].

During the period April-June 2009, the indicator was used to assess 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.

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 "test only") presence of the information or services in the examined web sites.

Construction of the *PWEI* indicator

PWEI, as pointed out above, is a multidimensional indicator, composed of a series of sub-indicators the objectives of which are 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.

Figure 1 illustrates how the main *PWEI* sub-indicators are linked to the main ambits of influence of ICT on the web sites of LHU and HT and the impact of these ambits on the two elements defining patient empowerment: information and control.

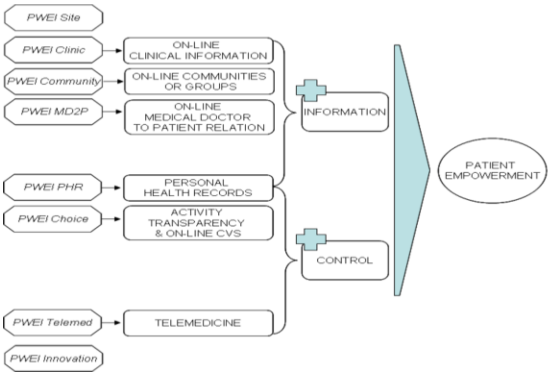

Figure 1 - The main influences of ICT on patient empowerment

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 of a number of these characteristics: 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. Site structure was examined, 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.). Menus constructed according to these approaches may aid consultation by patients presenting specific problems, who thus receive immediate answers targeting their specific needs. Lastly, an exhaustive description of the health organizations and their departments may aid the patients in that the description can be used as a map for orientation among the services provided: clear presentation of the organisational structure of the health unit was therefore also assessed.

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[1] 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.

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 of the presence of: i) leaflets or fact files on specific pathological states; ii) files dealing with prevention and for promoting correct lifestyles; iii) files to aid understanding of laboratory examinations; iv) healthcare provider magazines or newsletters with information regarding health and healthcare issues; v) back-up with guidance for self-diagnosis; vi) 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, online libraries).

The third component of the indicator is termed ***PWEI Community (P3)***. This sub-indicator assesses web site presence of on-line communities or of groups which ensure clinical back-up in the form of information, psychological support or a service consisting in accompanying patients with special health problems. The following entities were noted: i) institutional communities: counselling; on-line support centres (e.g. stop-smoking, dietary health problems, etc.); health organization linked voluntary associations; ii) bookmarks for Internet support group resources, i.e. direct links to medical sites or sites run by voluntary players or by patients; iii) lists of, and references to, non-web community and support group resources (generally, address directory mode).

A further indicator factor – 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: i) telephone line for counselling or general healthcare orientation purposes, ii) telephone line for health counselling on specific issues (e.g. influenza, contraception, AIDS, etc.), iii) use of personal email communication on the part of the organisation's medical doctors, iv) moderated institutional forums for communication among patients, v) blogs, forums or live sessions for communication between patients and medical doctors, vi) FAQ service on health issues providing medical doctors' 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 ones own personal health data. Sub-indicator *PWEI PHR* analyses openings for examining and downloading ones own electronic format record directly from the health unit's site or by other means (e.g. via electronic card or access on the part of the patient's general practitioner or specialist).

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, specialisation, 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: i) medical doctors' curriculum vitae data, ii) information on the typology and quantity of treated cases by pathological condition, iii) waiting lists for diagnostic services, specialist examinations and emergency room admissions.

The need to meet increasingly complex demands brings with it the need to re-configure the manners in which certain health services are provided, 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: i) specialist tele-counselling, ii) telehomecare iii) 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 of the index elements: ***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 sub-indicator was weighted according to its significance for the enhancement of patient empowerment[2]; weights were determined on the basis of scientific literature on patient empowerment and then validated with the involvement of a pool

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[2] A sensitivity analysys of the adopted weights is available upon request

of experts. The total value is reached by means of equation (1). The maximum theoretical value of the weighted PWEI is 10.

$$PWEI = 0{,}5\ P1 + 2\ P2 + 0{,}5\ P3 + 1.5\ P4 + 2\ P5 + 2\ P6 + 1\ P7 + 0.5\ P8 \quad \textbf{(1)}$$

Results

From analysis of the single *Patient Web Empowerment Index* indicators we learn that, as yet, few health organizations have developed web-based strategies oriented toward information and user control of clinical data. Although, nationally speaking, the presence of best practices was noted (above all, in Lombardy 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 can be assessed by geographic area (Table 1). Here, 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, the 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 still display an inability to implement the openings provided by the web for responding to patient needs.

Table 1 – Average PWEI by regional cluster (min 0- max 10)

	PWEI by regional cluster
Northwestern Italy	2.20
Northeastern Italy	1.85
Italy	**1.50**
Central Italy	1.07
Southern Italy	0.98
Islands	0.78

Particularly worthy of note is the prospect of *PWEI* sub-indicators analysis. The average national values for *PWEI* sub-indicators are listed in Table 2 (on a 0-10 scale).

Table 2 – National average values for each PWEI sub-indicator (min 0- max 10)

	Average Px value
PWEI Site (P1)	3.55
PWEI Clinic (P2)	1.10
PWEI Community (P3)	2.13
PWEI MD2P (P4)	0.94
PWEI PHR (P5)	2.79
PWEI Choice (P6)	0.32
PWEI Telemed (P7)	1.06
PWEI Innovation (P8)	0.46

The data indicate the greater significance of the *PWEI Site*, *PWEI Community* and *PWEI PHR* sub-indicators. For *PWEI Site*, the value is directly ascribable to the 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 units.

Discussion

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 P**WEI *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, medical doctors' 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 doctors of the organisation). Only on some sites are user-accessible forums and blogs to be found. Managed by counselling 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 ambits: i) single health organizations which independently decide to acquire systems for counselling and for patient downloads of electronic format health files; ii) *PHR* systems finalised 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 in the Lombardia and Emilia Romagna regions have solutions been devised for clinical data management on a regional level (the CRS-SISS[3] project for Lombardia and the SOLE[4] project for Emilia Romagna). 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 [7] [8].

Performance for telemedicine (***PWEI Telemed***) among health units is still unimpressive. A number of LHU especially in the Veneto, Emilia Romagna and Toscana regions, do have pilot projects, ranging from emergency telecare for infarcted patients to telehomecare for the elderly.

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. Managers' CV publication is foreseen by law at a national level as an admnistrative pro-transparency measure; real-time waiting lists data are available only on approximately fifty sites (at times, data are provided only for specific services).

Conclusions

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

- health units' awareness of the potentials of web instruments for curbing 'asymmetric information' situations (a typical characteristic of relations between medical doctor and patient) is only partial. Indeed, few organised resources have been made available such as provide solutions capable of responding to a broad range of health needs displayed by the citizenry;
- 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 views" (of waiting lists for services) 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 line of development of some interest for web strategies;
- the web strategies of health organizations basically reflect a state of immaturity. The strategies 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 site design seems to be well executed from the graphics angle and the information content is updated in a satisfactory manner, the logic behind design is still based on considerations regarding the concrete organisation of the structure. Patients may well not be familiar with such organisational aspects. By adopting this approach, transparency may be impeded with respect to specific needs.

Overcoming these three highly significant limits may turn out to be a prerequisite for concrete development of the provision of "healthcare 2.0" – a concept for innovation which healthcare systems are beginning to discuss.

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[3] The CRS-SISS (Regional electronic card 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.

[4] The SOLE (Sanità On-line), or on-line health care, 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.