

User-Centered Design for Citizens' Empowerment through the Portal of the Italian Ministry of Health

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ABSTRACT

In this paper we report on a study concerning the redesign of the Web portal of the Italian Ministry of Health, jointly conducted by the ministry and Sapienza Università di Roma. In this project, a multidisciplinary team consisting of computer scientists and engineers, sociologists and experts in communication, doctors and experts in public health was involved, in order to fully identify and understand citizens' needs in terms of health information, on the one hand, and to apply the most innovative methodologies and techniques for user-centered design and interfaces, on the other. Guidelines for on-line communication on protection and promotion of the health, and a mock-up for the future Web portal of the Italian Ministry of Health have been realized during the project.

Author Keywords

Web portal, taxonomies, guidelines, mock-up

ACM Classification Keywords

H.5.2 User Interfaces: User-centered design; J.3 Life and Medical Sciences: Health

INTRODUCTION

Current Web portals of ministries of Health, in Europe and all over the world, are evolving from simple information sites, mostly oriented to offer institutional and administrative information, to really interactive e-health systems, providing citizens and operators with various services related to health promotion and prevention, as well as facilitating the access to services of the National Health Systems (NHSs) (cf. <http://www.dh.gov.uk> and <http://www.nhs.uk> in the UK, and <http://www.bmg.bund.de> in Germany).

In this paper we report on a study concerning the redesign

of the Web portal of the Italian Ministry of Health¹, jointly conducted by the ministry and Sapienza Università di Roma, from February 2010 to January 2011. Sapienza participated in the project with a multidisciplinary team involving computer scientists and engineers, sociologists and experts in communication, doctors and experts in public health, in order to fully identify and understand citizens' needs in terms of health information, on the one hand, and to apply the most innovative methodologies and techniques for user-centered design and interfaces, on the other. The main products realized within this investigation have been:

- Guidelines for online communication on protection and promotion of the health and access to the Italian NHS [5], targeted mainly to Italian local (i.e., at the regional and municipal level) health administrations; such guidelines are focused on communication issues ("how to talk to citizens?") and on Web design suggestions;
- a mock-up for the future Web portal of the Italian Ministry of Health, together with its design specifications [8].

This work is part of the process of renewing the relationship between health organizations and citizens, in order to improve the condition of *empowered citizens*, repeatedly emphasized by the WHO (1978, 1986, 1998, 2005)². The empowered citizen is able to understand and choose, to define her own life-style, and to take an active role in managing her well-being, and is thus able to interact rationally and responsibly with those to whom she refer, i.e., the NHS. Empowerment means "giving power" to citizen. A citizen who has control over her state of health is a citizen able to participate in her own diagnostic, therapeutic, and rehabilitative processes, but she can act in this way only because she is informed. Even if a citizen is not yet a patient, provided health information could play a double role: on the one hand, it could prevent the onset of specific diseases, and, on the other hand, it could play an educational role that makes the citizen more aware of her rights and duties towards the NHS.

The aim of this experience paper is to present both the particular methodology adopted to produce the guidelines and the

¹<http://www.salute.gov.it>

²cf. the Alma Ata Declaration (1978), the Ottawa Charter (1986), the Jakarta Declaration (1998), the Bangkok Charter (2005).

mock-up, and the main technical innovations of the portal, in terms of interactivity and user interface. We therefore structure the paper as follows: Section 2 outlines the methodology and the activities carried out in the project; Sections 3–5 describe such activities and the related outcomes; Section 6 presents the redesign of the portal and describe the mechanisms used in the portal for semantic classification of contents to empower information retrieval; finally, Section 7 concludes the paper.

THE METHODOLOGY ADOPTED IN THE PROJECT

To devise the mock-up and the guidelines, we adopted a User-Centered Design (UCD) approach, which, as standardized in the ISO 13407, identifies four principal activities: *(i)* understand and specify the context of use, *(ii)* understand and specify the user and business requirements, *(iii)* design the product, in particular by creating a prototype, and *(iv)* evaluate the design.

In this project, we focused on *(i) – (iii)*, whereas activity *(iv)* is currently on progress. In the initial activities, the main challenge has been to understand the context and the requirements of a portal which potentially could be visited and used by millions of citizens. In particular, we had the need to obtain useful insights on the following questions:

- which are the health needs of the Italian population, i.e., what is the epidemiological situation of the main diseases and risk factors for diseases in Italy?
- who searches the Internet/Web for health information, which forms she adopts to surf the Web, and which kind of health information is actually looked for?
- what are other information needs in terms of protection and promotion of health that could be satisfied through online communication?
- what works on Internet/Web, i.e., which types of Internet/Web health interventions are actually efficacious and effective for improving health?

To this aim, we carried out our analysis in three main stages: *(i)* design and administration, for several months, of an online questionnaire, aimed at identifying the needs of the citizens using (also) Internet/Web to access health information and health services; *(ii)* systematic study of the literature concerning health needs and what has been discussed and demonstrated about the effectiveness of Internet-based interventions on public health; *(iii)* systematic analysis of a significative number of sites/portals of local health administrations, in order to derive possible best practices and to identify the critical points to be addressed.

Then, on the basis of the outcomes, a mock-up of the portal has been devised. The following sections provides some insights on the various activities. For the full details (including all the collected data) the reader is referred to [5].

THE ON-LINE QUESTIONNAIRE

In order to collect data concerning the online information needs of users of the Italian NHS, we have run a survey in the period ranging from April 14 to September 21, 2010, through the definition and the online administration of a questionnaire. The questionnaire considered the following

aspects:

- socio-demographic characteristics of the interviewees (age, sex, geographic area, education level, employment status);
- how they access Italian NHS Web sites;
- frequency of consultation of the Web, reasons for their consultations and main diseases included in their searches;
- which health promotion campaigns and which data on quality of the healthcare performances they would like to see advertised on NHS sites;
- how they evaluate the quality (i.e., completeness and usefulness) of online information currently available on the portals of the Ministry of Health and of other NHS organizations.

The questionnaire has been advertised on various sites, including the current portal of the Ministry of Health, the sites of some local health organizations, and on Facebook. We collected 2381 responses, 2324 of which have been analyzed, after checking the quality. 866 respondents were male (27%) and 1458 (63%) were female. 62% of the surveyed citizens use the Web especially for finding general information. Only around 30% use the Web in the first instance to search about a health problem, percentage that is relatively homogenous in different age groups; it varies from 23% for those who are 65 years old or more to 28% for those who are under 30. Around 58% of respondents prefer to search online information about the protection of the health rather than apply directly to a doctor. This is primarily due to the fact that through the Web they can immediately get some information. The information mainly searched includes: *(i)* specific diseases, therapies/treatments, side effects of therapies; *(ii)* hospitals or other medical facilities, booking systems for medical examinations, doctors or specialists; *(iii)* lifestyle. People look for information about the following diseases or health conditions: cardiovascular and/or lung diseases (23%); rheumatic and musculoskeletal diseases (16%); gastrointestinal diseases (gastritis, colitis, etc.) (12%); infectious and/or sexually transmitted diseases (9%); cancer (7%).

According to those who filled out the questionnaire, the health campaigns that should be promoted through the web sites of the Ministry of Health and other NHS organizations, as first option, should concern blood donation (20%), organ donation/transplantation (16%), workplace safety (13%), and responsible use of medicines (12%). If we consider more than one answer option for each respondent, preferences also include issues concerning the responsible use of drugs, screening cancers (breast, cervical and colorectal), proper nutrition/obesity. About half of the respondents consider important to find on institutional sites information on attitudes and actions necessary to maintain good health (49%), and indications concerning the levels of quality of health services provided by the local health organizations and hospitals (50%). For the 78% of respondents, the data on levels of quality should be published on the portal of the Ministry of Health. For what concerns the quality³ of health

³The quality of information is expressed in term of usefulness, accuracy, level of update.

information currently available on the Web, the best overall score has been obtained by the sites of associations of patients with specific diseases. Interestingly, the most useful information currently available on the portal of the Ministry of Health has been considered the one on transplantation, statistical data and materials on contests, announcements and legislation.

THE REVIEW OF THE LITERATURE

The epidemiological analysis of the health status of the Italian population was made through consultation of official data and reports of the Italian Ministry of Health, the National Observatory of Health of the Italian Regions and the National Institute of Statistics [4, 2, 3, 10].

To understand the Internet health information needs of the population, also in order to validate the online questionnaire, a systematic review of the literature was performed. A total of 52 cross-sectional surveys were retrieved, carried out mainly in the USA and Europe. The analysis of the three main surveys performed in USA, Europe and Italy [9, 7, 1] allowed us to identify the main determinants of Internet use for health purposes, the type of health information most frequently searched on the Web and other useful information. Gender, age and socioeconomic status are the major determinants of Internet use for health purposes. Women search the Internet for information about health more than men, even if they are penalized by the fact that they sometimes have less access to the Web. Younger people and people with high socio-economic level search more frequently the Internet for obtaining health information, but the quote of elderly and disadvantaged people using Internet for health is increasing. Specific diseases and specific treatments are the most popular topics searched through Internet. However, it is important to note that people searching the Internet for having information about health promotion activities and interventions for disease prevention are increasing, as well as people seeking information about access to health services and the performance of health care organizations. Although the main health related activity on the Internet is information seeking, a considerably increasing number of people use the Internet as a communication channel, participating in forums, self-help groups, etc. The increasing use of Internet to tackle isolation, to access experiential knowledge and for gaining social support should definitively taken in proper consideration when defining the Internet health information needs of the population.

The evaluation of the effectiveness of health interventions delivered through Internet is a difficult task. The field has suffered from a lack of clarity and consistency. The absence of professional leadership and of accepting governing approaches, terminology, professional standards, and methodologies has caused the field of the evaluation of these intervention to be diffused and unstructured. Only recently some categorizations have been proposed, as the classification proposed by Strecher [14], considering the ways that Internet can interact with the user: (i) user navigation; (ii) collaborative filters; (iii) applications; (iv) human-to-human interactions. Given the number of original studies evaluating the effectiveness of Internet health intervention, in this case the systematic search of the literature was limited to

systematic reviews and/or meta-analysis published in the literature. A total of 52 systematic reviews/meta-analyses fulfilled our predetermined inclusion criteria and were included for analysis. The methodological quality of the studies evaluating the effectiveness of Internet health intervention is not high, and the possibility of some conflict of interests cannot be ruled out in some situations. Despite these limitations, considering the most comprehensive reviews on the topic [14, 12, 11], it is possible to draw different conclusions: (i) the most effective Internet health interventions are the tailored interventions, with adaptation to the user, personalization and feedback; (ii) the sizes of these interventions could be categorized as small to medium for population-based interventions; (iii) however, the potential impact of these interventions on population health is high, and the cost-effectiveness ratio potentially highly favorable compared to other health interventions; (iv) however, common sense advices to implement hybrid models, which could combine applications or tailored interventions, user navigation, collaborative filtering, as well as human-to-human interactions, considering the high popularity of the latter ones among the Internet users.

The results of the review of the literature allow us to draw a set of recommendations for the construction of a national evidence-based health website. In summary it should:

1. contain information concerning the physiopathology of the human body, the most frequent diseases, risk behaviors, and health interventions of proven effectiveness, in order to improve the health literacy of citizens (cf. *Salute A-Z* in Figure 1);
2. include tailored interventions, with adaptation, personalization and feedback, aimed to promote healthy behaviors for disease prevention and compliance to secondary prevention programs of proven effectiveness (cf. the availability of applications on the portal, see Section 6);
3. give accurate information on the organizational structure of the national NHS, in order to facilitate the access to the health care organizations and, at the same time, to promote the appropriate use of them (cf. *Esplora SSN* in Figure 1);
4. contain information about the performance of the different health care organizations (hospitals, etc.) and, possibly, of physicians;
5. include systems and tools able to endorse the participation of citizens, as well as the human-to-human interactions (cf. the use of Web 2.0 tools, as discussed in Section 6).

AN ANALYSIS OF ITALIAN HEALTH WEBSITES

An analysis of Italian health organizations' websites has been carried out in order to obtain useful indications in planning for an effective online communication strategy. Its objective was to respond to the following questions:

- what kind of health information is available on the websites of such organizations (aims, logical information structure, content, online services, technologies, etc.)?
- do the websites satisfy the health information needs of the population concerning the available healthcare services, the promotion of public health and the prevention of diseases?



(a) Homepage



(b) Menu

Figure 1. The mock-up

- do they observe the standards set by the Italian e-government policy?

We have identified a set of indices and organised them in 4 dimensions, that explain the concept of “quality of online health information supply”:

1. institutional identity and networking attitude: the possibility to easily identify the site with a specific authority, and also its attitude towards the development of thematic and operative networks with other public health administrations or professional associations or patients’ associations working in the health service;
2. administrative transparency, based on the availability of online information regarding the organizational structure of the NHS, tasks and performance, and the availability of citizen protection mechanisms/tools;

3. availability and quality of the online services, concerning not only the quality of the website content and the use of Internet healthcare interventions, but also the quality (interactivity) of electronic forms and of facilities for on line booking of such services
4. accessibility and ICT quality, referring to the different solutions for presenting and organising the website content, regarding both accessibility for Internet users and technological criteria.

The analysis has considered the websites of all the Regional Governments (in fact, 19 regions and 2 autonomous provinces) and the websites of a sample of 84 Local Health Authorities (out of 195 in total). The main results of the analysis highlight that Regional Government health websites show:

- a strong institutional identity, because they present the local health policy as an outcome of the approach taken by Regional Governments and have a low international perspective;
- a weak attitude to networking with other public health administrations or private associations working in the local health service;
- a satisfactory level of administrative transparency, even though citizen protection mechanisms/tools are mainly normative statements;
- an high level of attention to the promotion of public health, even though they rarely make use of the communication campaigns offered by the Ministry of Health;
- a good level of ICT quality.

Instead, the websites of the Local Health Authorities are characterized by:

- a significant institutional identity, with frequent references to their respective Regional Government rather than to the Ministry;
- a good level of administrative transparency, even though the citizen protection mechanisms are mainly normative statements;
- a satisfactory level of availability of information regarding online services, even though electronic forms and facilities for online booking of health services are not very frequent;
- a good level of ICT quality.

Therefore, analyzing the websites of the Regional Governments and of the Local Health Authorities we can see a scenario revealing different online health communication strategies, with a strong local identity and with weak coordination by and towards the central institutional level (Ministry). In order to improve on line health communication, we suggested the following strategies:

- to recognize the centrality of citizens/patients, both in the phase of identifying and structuring the content of websites, and during the editing of the website and the organization of health services via the Internet;
- to strengthen the orientation and coordination role that the Ministry of Health should play in respect of other healthcare administrations as regards information and commu-

nication activities;

- to view online health information as the result of cooperative networking between the Ministry of Health and the other healthcare administrations (at national and local level);
- to build a network of health public administrations and professional associations and patients' associations working in the health services, aimed at exchanging information and strengthening mutual legitimacy, in order to reduce the fragmentation of information and to promote wider communication.

THE PORTAL

Figure 1 shows the homepage of the proposed mock-up. The four main pillars of the proposal are (i) a navigation interface, on the top of the page, based on "buttons" instead of the classical links, (ii) a large number of interactive applications, either accessible on the portal or downloadable on mobile devices, (iii) the possibility to customize the home page through the *MyPage* application (a-la iGoogle) and (iv) advanced search functionalities and page-to-page correlations based on taxonomies. In terms of contents, the (mock-up of the) portal respects the suggestions previously described.

The navigation menu based on buttons has the twofold aim of being aesthetically more catchy than the classical one, and ready for visualization on touch devices (e.g., iPads, touchpads, etc.), which represent the future of Web surfing. In order to enforce the citizen-oriented vocation of promoting good life habits, a lot of applications will be made available, e.g., for dietary calculation, alcohol abuse control, pregnancy check schedule, etc.; such applications, which enhance the level of interactivity of the portal and therefore attract users, can be mobile apps to be downloaded on devices, or Web applications accessible through the portal.

The possibility of customizing the page of the portal is an absolute novelty wrt existing public administrations/agencies, not only in Italy but, at the best of our knowledge, all over Europe. This has been obtained by including a *MyPage* application, which allows each registered user to personalize the information she wants to access.

The portal provides four main "channels", i.e., sections specifically tailored to particular categories of information and possible interested users: citizens (corresponding to *La nostra salute*), health and administrative operators (*Attività e professioni*), users interested in institutional and organizational information (*Ministro e Ministero*), and users interested in *News e Media*. Each section, which is managed by a specific editorial board, has its own space in the home page, even if, in compliance with the user-centered approach previously described, the section dedicated to citizens is predominant.

Moreover, in order to satisfy the suggestion 4 of Section 4, a specific information system, collecting quality and performance data of healthcare organizations, will be developed and made accessible through the portal. It is also worth remarking that Web 2.0 tools are used throughout the portal (e.g., tag clouds, wiki and blogs, correlations with Facebook, Twitter, etc.), in order to promote user interaction.

To provide users with powerful and effective means to retrieve the information they are looking for on the portal, its contents are being classified according to a *taxonomy*, i.e., a classification scheme which organizes in a hierarchical structure the main categories of interest in the domain. By virtue of this classification, the user can query the portal by referring to the categories of the taxonomy, and get as reply those documents that belong to the same or related categories. Notably, the reference to the categories does not need to be explicit, i.e., the user is not required to a priori know the taxonomy to pose queries to the portal (see also below).

In order to simplify the process of definition, validation, and maintenance of the taxonomy, and to ease the possible integration in the portal of contents coming from external information sources, to realize our taxonomy we analyzed existing (de-facto) standards. Among various proposals for content classification and terminological representation in the biomedical domain (e.g., UMLS⁴, ICD⁵, SNOMED CT⁶, GALEN⁷), in our project we referred to MeSH (Medical Subject Headings)⁸ a taxonomy developed by the National Library of Medicine (NLM) of the United States. This choice has been motivated by the fact that MeSH is specifically tailored to information retrieval (and thus suited to our aims), contains also non-biomedical or clinical categories, and with respect to other proposals has more compact dimensions (it includes around 22000 terms), which makes it simpler to use.

In fact, to make easier the process of content classification, we operated a simplification of the MeSH, aimed at both reducing the number of categories and eliminating the most technical ones. However, to not lose the advantages of adopting a (de-facto) standard, we simply "cut" some branches of the "MeSH tree" so as to exclude too detailed categories. In this process, we have been helped by domain experts. The resulting taxonomy contains around 3500 MeSH terms.

Despite MeSH includes general purpose categories (e.g., the ones of the *Disciplines and Occupations* or *Phenomena and Processes* branches), we found out cases in which MeSH results insufficient in order to satisfactorily classify some documents included in the portal. To overcome this problem, we decided to include in our taxonomy some of the categories used for article classification in (the Italian version of) *Wikipedia*⁹, and in particular we selected the categories included in the *Human Activities* branch of the *Wikipedia* classification schema¹⁰, which in fact substitutes in our taxonomy the (more limited) *Humanities* branch of MeSH. We chose the *Wikipedia* classification for two main reasons:

⁴<http://www.nlm.nih.gov/research/umls/index.html>

⁵<http://www.who.int/classifications/icd/en/>

⁶<http://www.ihtsdo.org/snomed-ct/>

⁷<http://www.opengalen.org>

⁸<http://www.nlm.nih.gov/mesh/meshhome.html>

⁹<http://www.wikipedia.org/>

¹⁰<http://it.wikipedia.org/w/index.php?title=Speciale:AlberoCategorie&target=attivit +umane&mode=categorie&dotree=Vai>

(i) Wikipedia is one of the most popular portal on the Internet, and its contents are widely shared among several millions of users; (ii) its category tree is designed through a collaborative process aiming at including categories proposed by the users, and therefore particularly suited for information retrieval activities.

We finally observe that, to further support the process of content classification in the portal, we foreseen the development of tools helping the research of the categories in the taxonomy. In this respect several directions can be followed: (i) realization of keyword-based search mechanisms to directly access the categories of interest in the taxonomy (thus avoiding to manually navigate the taxonomy); (ii) use of a dictionary (extending the one already available with MeSH) to include in the taxonomy also synonyms of categories, thus both expanding the lexicon of the taxonomy and including more terms in it, in a way transparent to the user; (iii) definition of techniques for automatic keyword extraction from text documents, in such a way that document classification could be done according to extracted terms, in the spirit of [6, 13]. More details on the taxonomy and the classification process in the portal of the Italian Ministry of Health can be found in [8].

CONCLUSIONS

In this experience paper we have presented a project, carried out during 2010, focused on the definition of guidelines for online communication on protection and promotion of the health in the Italian NHS (including regional health web portals, local health authorities websites, hospital websites, etc.), and the realization of a mock-up to serve as input for a redesign of the web portal of the Ministry of Health. The guidelines, as well as the mock-up, were successfully presented in a workshop on February 17, 2011. They are published online and are currently in the process of being formally adopted by all the interested administrations.

In a scenario in which all websites of the NHS organizations are realized in accordance with the guidelines, the portal of the Ministry of Health can be also able to act as a broker, in order to offer a centralized access to information and services of the NHS. An interesting future issue will be to consider how users will react, with respect to trust and privacy concerns, about the personalization features of the portal offered through the MyPage, as they may feel as their information access requests on the portal might be logged and analysed for potential medical information.

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