Provision of Tailored Health Information for Patient Empowerment: An Initial Study

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ABSTRACT

Search of "right" health information by patients/citizens is an important step towards their empowerment. The number of health information seekers on the Internet is steadily increasing over the years so it is crucial to understand their information needs and the challenges they face during the search process. However, generic search engines do not make any distinction among the users and overload them with the amount of information. Moreover, specific search engines/sites mostly work on medical literature and are built by hand. This paper analyses the possibility of providing the user with tailored web information by exploiting the web semantic capabilities and, in particular, those of schema.org and its health-lifesci extension. After presenting a short review of the main user requirements when searching for health information on the Internet, an analysis of schema.org and its health-lifesci extension is shown to understand the main properties and semantic capabilities in the health/medical domain. Finally, an initial mapping among user requirements and schema.org elements is presented in order to provide expert and non-expert user categories with web pages that satisfy their specific requirements.

CCS CONCEPTS

• Information systems → Clustering and classification • Information systems → Information extraction • Information systems → Users and interactive retrieval • Information systems → Specialized information retrieval • Information systems → Personalization • Information systems → Web searching and information discovery • Applied computing → Health informatics

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KEYWORDS

Patient Empowerment, Health Information Seeking, User Requirements, Structured Data on the Web, schema.org.

1 Introduction

Health and care systems are changing rapidly and, nowadays, patients, or citizens in general, are not seen any more as passive recipients of a unidirectional stream of information, that comes from the medical professionals, but as active participants of a two-way continuous relationship with them. To this end, patients and citizens need to go through an *empowerment* process, i.e., a process through which people gain greater control over decisions and actions affecting their health [1]. Search of "right" health information is an important step towards their empowerment.

In line with the empowerment process, [2] reports that health information seekers are those people who seek to clarify, confirm or question advice from health professionals through their search and assessment of online health information sites. The number of health information seekers on the Internet is steadily increasing over the years [3], [4] so it is crucial to understand their information needs and the challenges they face during the search process. Although search engines are typically used by health information seekers as the starting point to search for information [4], [5], keyword-based searching has been shown to be limited and unsatisfactory for online health information [6], [7]. In particular, generic search engines (e.g., Google©, Bing© or Yahoo©) exploit the whole web but make generic searches, often overloading the user with the provided amount of information. Moreover, they are not able to provide specific information to different types of users. On the other hand, specific search engines, such as PubMed[1] or Cochrane Library[2], mostly work on medical literature and provide extracts from medical journals that are mainly useful for medical researchers and experts but not for non-experts. Moreover, they do not consider all the information contained in the web that may provide additional insights.

In this paper, we analyse the possibility of facilitating the search of web information by health information seekers by exploiting the semantic capabilities of schema.org and in

[1] https://www.ncbi.nlm.nih.gov/pubmed/
[2] https://www.cochranelibrary.com/

particular of the health-lifesci extension. To this end, we first present a short review of the main user requirements when searching for health information on the Internet. We then make an analysis of schema.org and its health-lifesci extension to understand the main properties and semantic capabilities in the health/medical domain. Next, we present an assessment of schema.org to provide different user categories (i.e., experts and non-experts) with web info that satisfies the different user requirements and show a preliminary mapping among the user requirements and the schema.org elements.. Finally, we present some conclusions and future work.

2 Requirements of health information seekers

We now report the results of a short review we have carried out in order to understand what are the requirements of the users when they search for health information on the Internet so that they can get the specific information they are looking for in a quick and easy way.

Banna et al. [2] have conducted a study on user requirements for interactive online health services. In particular, health information seekers fully agreed with the following statements:

- I feel that the language used must be easy to understand (i.e. medical terms simplified to non-technical language and if not, there is a glossary or online medical dictionary);
- I feel that it is important that the quality of information provided on this website is scientifically correct.

Pletneva et al. [8] present the results of a survey on how the ideal citizen-centred health search engine should be made. First of all, they show how the information should be presented. 54% of respondents have chosen the categorization approach when all the links are grouped into scientific, clinical, commercial, advertising, forums and blogs. 24% would prefer a summary referencing the different sources, and 20% like the "conventional" form of search result presentation as a list of links (such as Google®). Users also want to know if the information they search for exists on the Internet, and whether it is explained in the same way their doctor would.

Roberts [9] presents some techniques for effectively searching the Internet for health information. In particular, it provides some tips for evaluating the quality of health information on the web by suggesting to understand what is the source of the web information, whether the site has and editorial board, how often the information is reviewed and who pays for the site (this could lead to biased information). It also suggests how to find doctors, hospitals, health agencies or pharmacies (in the New York State) by looking at specific web sites. Interestingly enough, it emphasizes the overall importance of talking to a doctor about the health information found on the Internet because the "patient-doctor partnership can lead to the best care and medical decisions".

Plan et al. [10] talk about tailored health information as specifically designed for specific people based on their unique needs and interests. They say that tailored health information has been shown to be effective in increasing user's knowledge and understanding of health issues and influencing health behavior change. Hence, tailored health information has more impact on users' understanding and knowledge because the information is more relevant to the users' situation and needs.

Pang et al. [11] present four categories of health information seekers and a "better health explorer" that allows them to find more easily the desired health information. The system presents, among others, some sliders that allow to specify the information categories, the reading level and whether the text should contain more text or images/videos.

Keselman et al. [12] affirm that to support users with limited health literacy and bridge the digital divide, resources should aim at tailoring information content and presentation to intended users, or targeted audiences. Moreover, reaching health consumers with the appropriate information can be improved via further development effort in the areas of consumer health vocabularies, information retrieval, and readability. Finally, more accurate, well-publicized information quality indicators will benefit health consumers.

Table 1 reports a summary of the findings on the user requirements discussed above.

Table 1. User requirements of health information seekers.

Paper	Language Complexity	Information Quality	Information Classification/ Customization	Other
[2]	✔	✔		
[8]	✔	✔	✔	
[9]		✔		
[10]			✔	
[11]	✔		✔	✔
[12]	✔	✔	✔	

Although limited, the literature review presented above shows that the main requirements of health information seekers are the following:

- Language complexity
- Information quality
- Information classification/customization

In the next sections, we will see how the semantic properties present on the web, such as the ones of schema.org, can be used for providing online users with the health web content that satisfies their requirements.

3 Analysis of schema.org and health-lifesci ext.

As discussed in the previous section, we now investigate the possibilities offered by structured data to find suitable web pages that satisfy the requirements of health information seekers. To this end, we exploit the semantic information available in the World

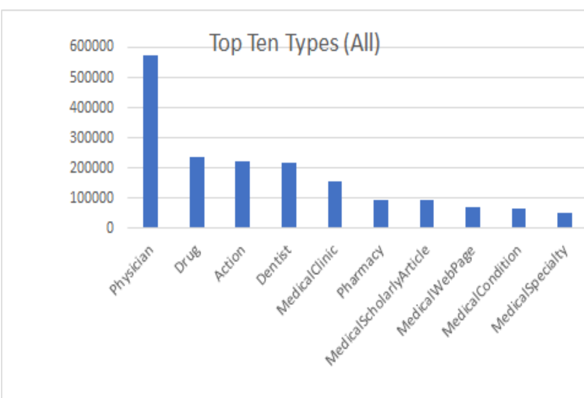
Wide Web and, in particular, the one provided by schema.org[3], an initiative founded by some major web players, that aims to create, maintain, and promote schemas for structured data on the Internet. For the scope of the present work, we consider the health-lifesci extension[4] that contains 93 types, 175 properties and 125 enumeration values related to the health/medical field.

We have performed an analysis of the health-lifesci elements using the data made available by the Web Data Commons initiative[5]. The Web Data Commons (WDC) [13] contains all Microformat, Microdata and RDFa data extracted from the open repository of web crawl data named Common Crawl (CC)[6]. The data released in November 2017 has been used in this work. The whole dataset contains about 3.2 billion pages, with about 38.9% of them presenting structured data.

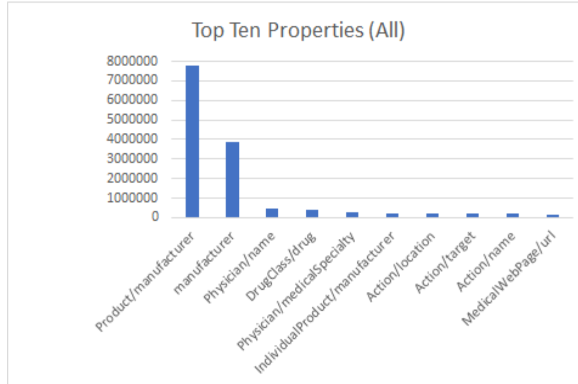
The dataset dump available on the Web Data Commons web site, that we used in our study, consists of 38.7 billion RDF quads[7]. These are sequences of RDF terms in the form {s, p, o, u}, where s, p and o represent a triple consisting of subject, predicate, object and u represents the URI of the document from which the triple has been extracted. We have extracted a subset of 21,672,984 quadruples that contain all the types, properties and enumeration values of health-lifesci.schema.org.

We have analysed the subset to understand the number of the health-lifesci.schema.org elements and, in particular, types and properties. The results of this analysis are available at the address http://h-easy.lero.ie/opendata/. Fig. 1 shows the top ten types and properties.

Notice that, although, we have extracted types, properties and enumeration values of health-lifesci.schema.org, some types, such as *action*, are generic ones and also belong to the schema.org core elements.



(a)



(b)

Figure 1. Top ten types (a) and properties (b) of health-lifesci.schema.org.

The same applies to properties, such as *manufacturer* (that has the highest frequency and repeats in different properties) or *Action/location*, *Action/target* and *Action/name*, which are generic and belong to the schema.org core elements. As a consequence, a number of triples (and related URIs) that present these properties do not belong to the health/medical domain.

In order to eliminate, or at least sensibly reduce, the number of unrelated triples and URIs, we have extracted the Pay Level Domains (PLDs) and the triples associated to them. Moreover, we have evaluated whether each PLD is dealing with health/medical topics. The complete results of this analysis are available at the address http://h-easy.lero.ie/opendata/ and Table 2 shows the top ten results.

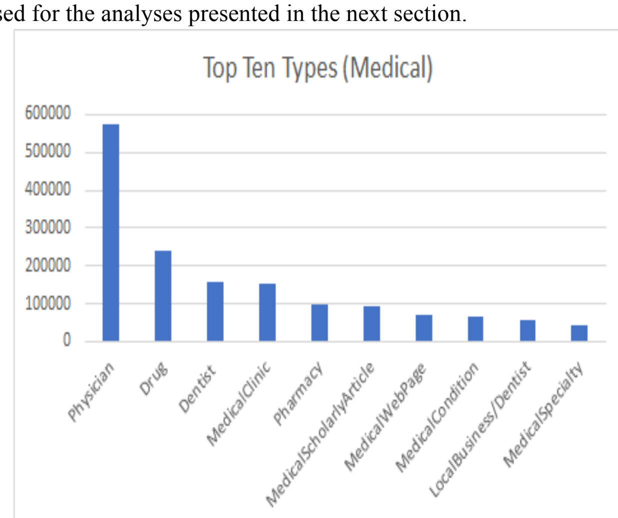
Table 2. PLDs with # of quads and health/medical indication.

#quads	PLD	Health/Medical
964731	spreadshirt.com	no
853482	poptop.uk.com	no
744302	goodrx.com	yes
527509	spreadshirt.de	no
498985	shop.spreadshirt.com	no
454373	carroya.com	no
429029	sehat.com	yes
370701	propartner.ru	no
364971	malacards.org	yes
356559	zamienniki.sprawdzlek.pl	yes

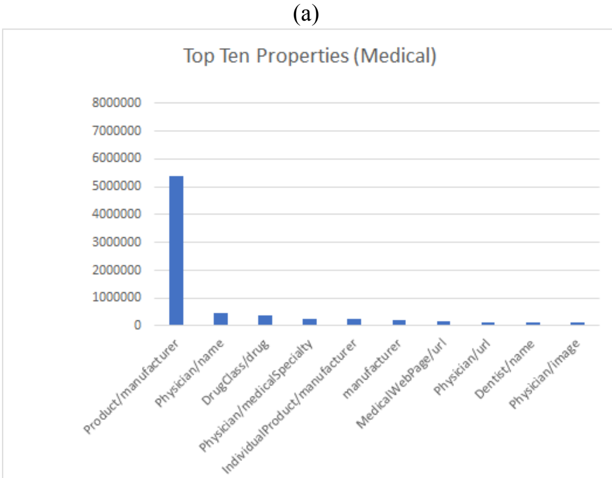
[3] https://schema.org/
[4] https://health-lifesci.schema.org/
[5] http://webdatacommons.org/
[6] http://commoncrawl.org/
[7] https://www.w3.org/TR/n-quads/

As a consequence, we have eliminated the non-medical PLDs (and related quadruples) from the subset and we have analysed again the numerosity of the health-lifesci.schema.org types and properties obtaining the results available at the address http://h-easy.lero.ie/opendata/. Fig. 2 shows the top ten types and properties of the new subset. Fig. 2a is quite similar to Fig. 1a but does not present the generic *action* type. On the other hand, Fig. 2b is quite different from Fig 1b because it still presents the *manufacturer* property but with a much lower frequency and the *Action/location*, *Action/target* and *Action/name* properties are gone and have been replaced by medical properties.

The obtained "health/medical" subset of quadruples has been used for the analyses presented in the next section.



(a)



(b)

Figure 2. Top ten types (a) and properties (b) of health-lifesci considering health/medical PLDs.

4 Mapping health information seeker requirements to schema.org elements

As seen above, when seeking for health information on the Internet, users have different requirements and in this section, we present an assessment of the schema.org elements that can be used to provide web information tailored to the different user requirements.

The first requirement reported in Table 1 relates to the web page language complexity level. Usually, non-experts require the used language to be easy to understand whereas medical experts require a more technical and precise language.

In order to provide the different user categories with web pages with proper language, we have considered, in another work [14], the "health/medical" subset described in the previous section and we have extracted the quadruples related to *Patient*, *Clinician* and *MedicalResearcher* health-lifesci elements. These are subtypes of the *MedicalAudience* type and describe the target audiences for the medical web pages. For each subtype we have obtained a subset with the following number of quadruples:

- Patient: 36,186
- Clinician: 15,913
- MedicalResearcher: 3,458

Next, we have analysed the English and non-empty web pages of each subset (around 50%) and, for each web page, we have computed its language complexity level. This has been done by computing the 'term familiarity index' [14], [15], [16] of each page term (as the number of Google results) and then calculating the average for the page.

The experimental results, presented in [14], show that the web pages targeted to *Patient*, present, on average, a much higher term familiarity index and thus a simpler terminology whereas the web pages targeted to *Clinician* and *MedicalResearche*r present, on average, a lower term familiarity index and thus a more complex terminology, even though *Clinician* pages are a little closer to *Patient* pages. As a consequence, from the language complexity perspective, *Patient* web pages (with a high term familiarity index) can be provided to non-experts and *Clinician/MedicalResearcher* web pages (with a low term familiarity index) can be provided to medical experts.

For what concerns the other two requirements, i.e., information quality and information classification/customization, we have executed some experiments that help us in creating a mapping among the user requirements and the schema.org elements. In particular, we have taken the three subsets of web pages containing *Patient*, *Clinician* or *MedicalResearcher* healht-lifesci audience types and, for each web page, we have extracted and counted the schema.org elements (including the health-lifesci ones) of that page. Notice that the web pages related to the *MedicalResearcher* audience belong almost completely to the malacards.org PLD (2080 out of 2099) and actually contain all the three target audiences. As a consequence, they do not provide us with distinctive features regarding the audience categories and, for this reason, they have not been considered in this analysis.

The complete results of the performed analysis are available at the address http://h-easy.lero.ie/opendata/. As a first step, we have focused on the health-lifesci elements and Fig. 3 shows, for the non-expert (Patient) and expert (Clinician) audiences, the health-lifesci.schema.org types that appear more frequently (each element has been counted only once in each web page). The first fifteen elements of each category have been considered because they mostly present a number of occurrences of at least 5% of the number of Patient and Clinician web pages. Moreover, the number of occurrences has been normalized, respectively, to the number of Patient and Clinician web pages in order to be able to make a comparison between the two audiences.

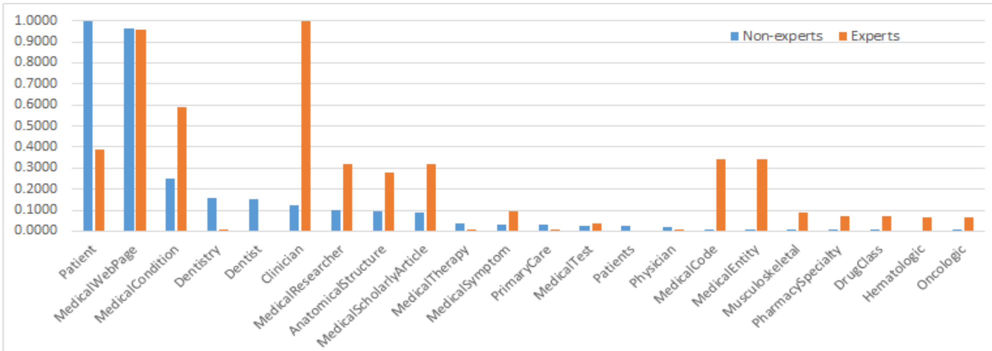


Figure 3. Most recurrent health-lifesci.schema.org elements in *Patient* and *Clinician* web pages.

By examining Fig. 3, we can draw the following considerations:

- The health-lifesci elements of non-experts (*Patient*) are quite separated from the ones of experts (*Clinician*) indicating that, in general, web pages targeted to non-experts contain different types of information from the web pages targeted to experts. Only *MedicalWebPage* has a comparable number of occurrences indicating that it cannot be taken as a distinctive feature of one of the two user categories. This is easily explained by the fact that *MedicalWebPage* just indicates that the web page provides medical information and this applies to both non-experts and experts web pages.
- *Clinician* and *MedicalResearcher* target audiences appear in *Patient* web pages because there are web pages that contain all three target audiences (the ones belonging to malacards.org PLD, as seen above).

As a second step, we have drawn the concept graphs of all schma.org elements (including health-lifesci elements) associated to *Patient* and *Clinician* audience types. Fig. 4 and Fig. 5 present these graphs.

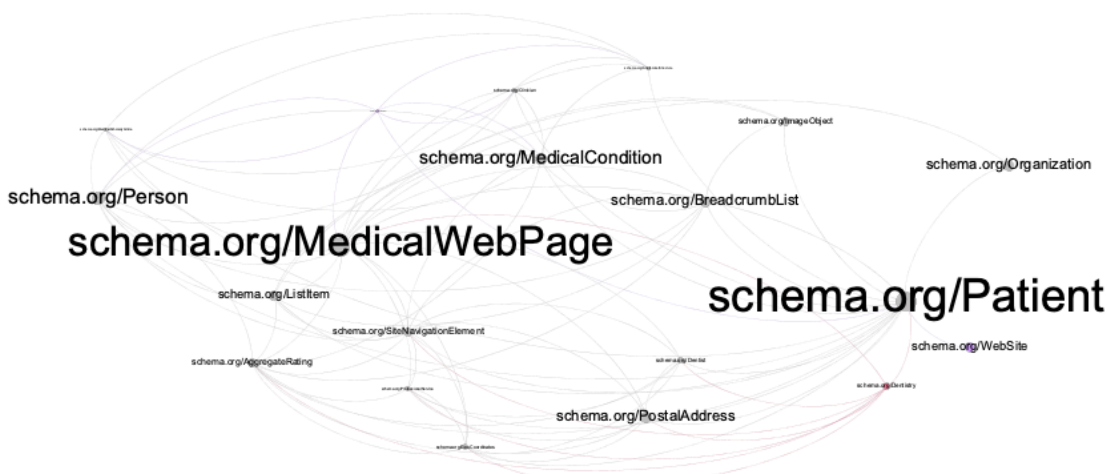


Figure 4. Concept graph of schema.org elements associated to the *Patient* audience type.

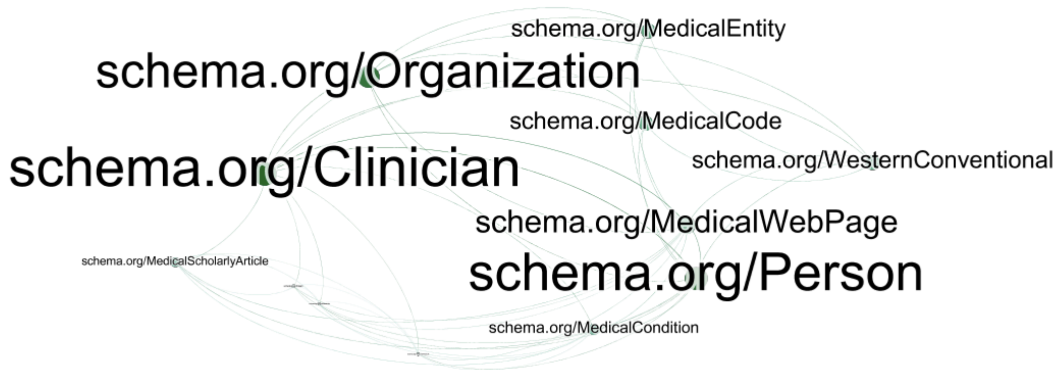


Figure 5. Concept graph of schema.org elements associated to *Clinician* audience type.

From the analysis of data represented in Fig. 3, Fig. 4 and Fig. 5, we draw the following conclusions:

- The health-lifesci elements of the non-experts provide information on general medical aspects such as *MedicalCondition* and *MedicalTherapy* and information about the medical experts and institutions (as emphasized by the presence of *Person*, *Organization* and *Postal Address* in Fig. 4). The information is usually provided in a language easy to understand (as seen in [14]). All these elements can be used to provide classified and customized information to the non-expert user category.
- The health-lifesci elements of the experts provide information on general medical aspects such as *MedicalCondition*, *AnatomicalStructure*, *MedicalSymptom,* and *MedicalScolarlyArticle* but with a more technical language (as seen in [14]). Moreover, information on specific medical aspects is provided by using elements such as: *Muscoloskeletal*, *Hematologic* and *Oncologic* (Fig 3). Finally, codified and institutional information is provided by using elements such as *Organization, Person MedicalCode*, *MedicalEntity* and *WesternConventional* (as shown in Fig. 5). As reported in the schema.org website, *WesternConventional* represents "the conventional Western system of medicine, that aims to apply the best available evidence gained from the scientific method to clinical decision making". All these elements can be used to provide classified and customized information to the expert user category.
- The experimental results did not provide us with specific data that can be immediately used for information quality. Although a deeper investigation is needed, from an analysis of literature [17], [18], [19], some schema.org elements such as *author* and *publisher* (for reliability) and *dateCreated* and *dateModified* (for timeliness) can preliminarily be used to indicate information quality.

Table 3 summarizes the experimental results by providing a preliminary mapping among the different requirements of the two user categories and the health-lifesci.schema.org elements.

Table 3. Mapping among health information seekers requirements and health-lifesci.schema.org elements.

	Language complexity	**Info Quality (Reliability, Timeliness, etc.)**	**Info Classification/Customization**
Non-expert	Simple language *Patient* (with high term familiarity index)	Reliability (schema.org *author, publisher*, ...) Timeliness (schema.org *dateCreated, dateModified, ...*)	Information on general medical aspects (*MedicalCondition, MedicalTherapy*, ...) Information about expertise and institutions (*Physician, PrimaryCare, ...*)
Expert	Technical language *Clinician* *MedicalResearcher* (with low term familiarity index)	Reliability (schema.org *author, publisher*, ...) Timeliness (schema.org *dateCreated, dateModified, ...*)	Information on general medical aspects (*MedicalSymptom, MedicalTherapy*, ...) Information on specific medical aspects (*Oncologic*, *Muscoloskeletal, Hematologic*, ...) Codified information (*MedicalCode*, *MedicalEntity*, ...)

As seen above, the first user requirement regards the language complexity (simple and technical) and it has been already extensively discussed in [14].

The second user requirement relates to Information Quality that is usually measured in terms of accuracy, reliability, completeness, legibility, timeliness, accessibility and usefulness [17], [18], [19]. From a first analysis this information is contained in the core elements of schema.org. As said above, although there is no evidence of such elements in the collected data, some schema.org elements that can be used to indicate information quality are *author* and *publisher* for reliability and *dateCreated* and *dateModified* for timeliness. Notice that the PLD can also provide an information on the "authority" of the information source and, consequently, the quality. Nevertheless, a focused analysis of the schema.org core elements should be conducted for evaluating their use in quality assessment, but this is outside the scope of this work. Of course, information quality is a cross-category requirement, i.e., good quality web information is of interest to both experts and non-experts.

The third requirement relates to Information Classification and, as seen above, we have different types of classifications. Non-experts may be interested to receive information on general medical aspects such as symptoms, conditions and therapies or information about medical experts and medical institutions. Looking at the health-lifesci.schema.org elements, we could use, for example, *MedicalCondition* or *MedicalTherapy* elements for the first group of information and *Person* or *Organization* for the second group of information. For what concerns experts, they may be interested in receiving information on the same general medical aspects such as symptoms and therapies, but with more medical/technical details. Moreover, experts can be interested in information on specific medical aspects (such as oncology, musculoskeletal, hematologic) or in codified information, as is in the case of medical controlled vocabularies or ontologies (e.g., ICD-9, MeSH and SNOMED-CT). In the former case we would use elements such as *Muscoloskeletal*, *Hematologic*, *Oncologic,* and in the latter case, we could use elements such as *MedicalEntity* or *MedicalCode*.

The experimental results are quite satisfying because they provide an initial information classification, as the one presented in Table 3, that allows us to provide customized information to the different user categories. Nevertheless, a deeper analysis and experimental phase is needed in order to better understand how each schema.org element can contribute in providing such focused information.

5 Conclusions and future work

In this work, after presenting a short review of the main user requirements when searching for health information on the Internet, we have made an analysis of schema.org and its health-lifesci extension to understand the main properties and semantic capabilities in the health/medical domain. Moreover, we have presented an assessment of schema.org and health-lifesci elements and a first mapping that allows us to provide different user categories (i.e., experts and non-experts) with web information that satisfies the user requirements.

Of course, as said above, more experiments need to be executed in order to better understand the correlation between the user requirements of the health information seekers and the contribution that can be provided by the schema.org elements. In particular, we plan to use the co-occurrence of specific types and properties as features for implementing a classification engine based on the semantic annotations included into the Web pages. Moreover, we plan to analyse the image features [20], [21] in order to complement the text and to provide the different audience types with a tailored multimedia information. Finally, we are in the process of running some tests with real users in order to understand the effectiveness of the achieved results and to co-design the next steps based on their specific requirements.

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