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# Health Literacy in Complex Digital Information Environments

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## Chapter 3

# Health literacy in complex digital information environments

[PRE-PRINT]

### 3.1 Introduction

Health literacy must now be considered and studied, taking into account digital environments as well as the information on offer that users and patients may encounter online. Work in the field of health literacy has been going on for about 40 years. The concept appeared in 1974 [SIM 74], the same year as the concept of information literacy [ZUR 74]. Similarities between the two literacies can be seen both in terms of definition and content, particularly because the main issue in health literacy is information. The concepts of preventive medicine or therapeutic education are not totally removed from the aspects covered by the term. Health literacy appears to be a broad and encompassing concept that is not limited to medical literacy. Indeed, it concerns users who are not necessarily patients [PEE 09, SAU 09]. Informational and digital health practices are now frequent and are also

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<sup>1</sup>Chapter written by Eloria VIGOUROUX-ZUGASTI, Olivier LE DEUFF and Amar LAKEL

carried out outside the health care pathway. However, the sites and forums of patient communities are becoming better recognized elements in the health care pathways.

This chapter thus seeks to show the evolution of the concept and its realities in relation to the transformation of the supply of health information. We wish to understand the relationships between health literacy and other literacies that seem to be close to it: information literacy, digital literacy, information literacy and digital culture [BAW 01, LED 11], etc. Indeed, it appears more and more as a cross-disciplinary literacy or transliteracy [THO 07], combining several types of literacy (informational, media, health, etc.). Therefore, the question of the level or measurement of this literacy seems complex to assess, despite assessment instruments that try to take into account a maximum of criteria. Like many other literacies, health literacy appears to be regularly in crisis [GRA 87]. It sometimes gives rise to concern on the part of national or international institutions, especially since it is not only an intellectual or cultural literacy, but a major public health issue. Recent definitions try to take these parameters into account. The 1998 definition shows its importance: "Health literacy represents the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand, and use information in ways that promote and maintain good health"<sup>2</sup>. It is on this broad conception of health literacy – which we will furthermore refer to as "digital health literacy" - that our scientific approach is based.

In the first part, we will open a discussion on the issue of global mixed methods that we have mobilized in research projects on health information on the Internet, particularly in the context of our participation in the EUR "Bordeaux Public Health"<sup>3</sup>. In a second step, we will review the results of our surveys on the web dimension of health research and on the connected uses of elders dedicated to this topic. The results will be based, on the one hand, on quantitative data from web analysis and, on the other hand, on qualitative data from interviews with seniors. Finally, we will show in a third part the benefits of conceiving digital health literacy as a literacy dedicated to considering health information on the Internet as an important factor of therapeutic education, which is currently at the heart of public health policies.

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<sup>2</sup>. Health PromotionGlossary. World Health Organization, Geneva. <https://www.who.int/healthpromotion/about/HPR%20Glossary%201998.pdf?ua=1>

<sup>3</sup>. My Web Intelligence in health information project (2014 - 2017, Conseil Régional - Direction du Numérique), Information Risk in Seniors and Self-Medication project (2015-2016, Université Bordeaux Montaigne and MAIF Foundation)

### **3.2. Analyzing health information on the Internet: the need for a mixed and comprehensive approach**

Understanding the process of influence on the Internet is a major but complex issue for social science research. The object itself, despite a century of research, is still poorly defined. Influence is the effectiveness of an act of power in that it aims to act on the actions (or representations) of another person [LAK 08]. Research on the side of the influencers (i.e. on their capacity to influence) must take into account the social characteristics of the speaker, their communicative practices, the social system in which they act and their role in hierarchical networks of actors. On the side of the influenced, it is the research on literacies as a key concept that allows us to understand the learning and subjectivation paths. Influence and Literacy are the two visible sides of the same coin that aims at studying the web as a medium of transformation of informational practices.

#### ***3.2.1. Approaching public health information literacy through the lens of information quality in ICS***

The first approach to the question of health information on the Internet, from the point of view of the ICS, consists of studying the structure of the offer, aiming to set up the conditions for a sociology of digital transmitters and even influencers. An examination of the scientific corpus that studies the supply of health information, particularly on the web, shows that a high proportion of articles come from Public Health research (Social Sciences and Health) and that the Humanities and Social Sciences, in general, only deal with this subject in less than a third of the corpus (ICS journals being almost not represented) [LAK 19]. This corpus can be classified into three main scientific approaches. Firstly, for public health researchers, it is a matter of examining the quality of content with respect to the norms of medical discourse by giving (bad) marks to online content. A second approach, based on a sociological approach, analyzes the rise of the patient's voice, which tends to redefine the traditional discursive economy in Web 2.0 spaces (blogs, forums, social networks, etc.).

As for the Public Health approach in ICS, it specifies this research axis by insisting on the new economies of content, by developing an analysis of discursive regimes in the framework of a critique of the cultural industry. Much more than a

sociology of actors, the challenge here is to pay attention to the sociosemiotic markers of discourse.

The first line of research, in public health (section 46 of the *Conseil National des Universités* (French National Council of Universities)), attempts to evaluate digital corpora with respect to the standards of medical publications on a scale of scientific quality. The quantitative approach is very formalized and quite stable from one article to the next. This methodological constancy is strongly conditioned by the disciplinary homogeneity which leads to the same analysis models being repeatedly applied to different corpora. The idea is therefore to find the doctor's voice on the Internet and to evaluate its quality with regard to the standards used in health (learned societies, medical recommendations, etc.). We therefore naturally exclude patient forums and blogs whose discursive regime is clearly considered by the public health researcher as irrelevant, even though it is prolific on the web.

Researchers then rely on objective and institutional evaluation grids such as DISCERN, HON, NetScoring or even the standards of the European Commission. In most cases, researchers combine these standards to propose their own evaluation grid [ESP 14, FRE 01]. The results of the analysis are not very surprising. Non-medical corpora are not "good" medical corpora. The presence of the medical profession very often exceeds half of the corpus and patient associations and patients themselves are barely represented (around 10% in most articles). Half of the discourse is addressed to professionals and in more than half of the cases the author is not identifiable, nor the date, nor the updates. The authors quite often recognize that good bibliographic references are present, but often insufficient. For two thirds of the pages analyzed, they are considered mediocre if not bad. The actors recognize that there is very little dangerous information, but that the corpus is overall quite poor. Added to this, longitudinal studies show a strong instability of the corpus from one year to the next with more than half of the corpus disappearing from search engines for the same query. When it is not clearly judged to be of no interest whatsoever [ESP 13], the word of the patient and his expectations are described as having little interest in terms of medical legitimacy.

The second line of research, stemming from digital sociology and ICS, is based on a qualitative approach to online discourse that is close to the paradigm of pragmatic interactionism. If the corpus proves to be neither exhaustive nor representative, these "exploratory studies" remain cautious as to the representativeness or even the generalization of their observations because of the

impossibility of constituting either a reference population or a representative sample [LAK 19]. By relying both on the formal description of interaction sequences based on the Goffmanian model and on a lexical analysis of thematized discourse, the approach of this research focuses on the emergence of new discursive strategies of patients and caregivers [CON 03, STAI 10, PAG 14]. All this research seems to stabilize in a field of hypotheses distributed on three levels: strategic, pragmatic and stylistic [BAT 13; PAG 14]. On the strategic level, it is the patient's voice that seems to be the focus of all attention. The research in SHS then focuses on the emergence of a new discursive regime that is very present in these digital spaces and that gives them their own specificity. It is a regime of personal testimony, of individual lived experience, which founds the specificity of ICS approaches.

Faced with these two approaches, we wanted to develop an open quantitative approach based on the development of a tool for extracting (crawler), archiving and qualifying the Web for digital studies, that can remove the constraints currently weighing on the constitution of online corpora: My Web Intelligence<sup>4</sup>. The objective is to provide all experts and researchers who wish to develop studies in the field of digital intelligence, digital humanities and sociology of the web with a simple device for building a web corpus representative of an open controversy. The constitution of digital corpora for social science research is then at the heart of what we have called the tests of digital methods [COR 19].

From queries founding a semantic dictionary on a disease, we obtain, from two search engines (Google.fr and MSN.fr), 1235 relevant pages that we group in a second data set at the level of expression domains<sup>5</sup>. In this research, we start from the usage scenario of an average French Internet user asking about a disease. The terms were chosen to be neutral and short in order to cover the most open sample possible<sup>6</sup>. In this research, we wanted to avoid the sampling bias introduced in previous studies by a socially situated vocabulary. As we have seen, the choice of a

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<sup>4</sup>. *My Web Intelligence* is today a prototype platform created within the MICA and which runs in a python environment on a SQLite database: <http://mywebintelligence.net>

<sup>5</sup>. The expression domain is not quite the domain name because in the case of content farms (social networks, blogging platforms, etc.) we had to develop heuristics to split these domain names into sub-domains corresponding to editorial units (pages, profiles, groups, etc.). In this study, we retained 846 domains of expressions.

<sup>6</sup>. Our research aimed to study web pages addressing the topic of asthma in children using the words "*asthme*, *asthma*" associated with "*jeune*, young", "*enfant*, child", "*bébé*, baby", "*nourrisson*, infant", "*infantile*, infantile" and "*adolescent*, teenager". For more details on the methodology see [LAK 19]

socially situated vocabulary necessarily over-represents the populations usually using these keywords. Technical words, scientific or familiar words, affective words, the lexical field chosen in the dictionary of queries is necessarily a sampling bias. We measure that the meaningful web for a user of these search engines is a limited web, because it is formally structured by the ranking algorithms of these infomediaries, socially structured by the marketing strategies of the speakers and intentionally structured by the receiver's query. In fine, these three rules lead to the constitution of a corpus biased by the semantic field used in the retrieval requests.

### **3.2.2. My Web Intelligence: a model for analyzing health information controversies**

The first level of analysis is therefore the page containing a statement about asthma in children. A first automatic extraction obtains the complete HTML code, the title, the URL, the description contained in the meta tags. Then algorithms ensure a first layer of extraction by detecting the main content of the document (readable); the URLs of links (urls), images (imgs) and videos (videos) at the heart of this content. The goal is to build the document's citation network. An extraction by crawling at several depth levels enriches the corpus. The depth variable reminds us if the document was obtained at the start (level 0) or by extraction (level n).

In addition to this first level of extraction, there is an automatic level of external extraction via web services by API. At this stage, we find the measurement of the social resonance of the URL (*facebook\_like*, *facebook\_share*, *linkedin\_share*) which remains to this day the only global indicator of a page's impact. Indeed, the first limitation lies in the access to information that measures the use of a content. Between the beginning of the project and its end (18 months), we saw all the social networks close their API doors and more and more indicators were no longer available. We were only able to keep the *likes* and shares on Facebook. This problem highlights one of the major limitations of *digital methods* that access data that are owned by private companies that play an arbitrary role in controlling access to their resources for research purposes [COR 19]. In a third step, a human annotation allows us to contextualize the document thanks to three variables: the publication date (*publication\_date*) on the Google search engine, the media type (*media\_type*), and the emitter type (*emitter\_type*), which we have deliberately kept open.

Finally comes the set of structural network analysis algorithms (Social Network Analysis) from the hyperlinks of internal citations in the corpus [SCO 17, WAS 94].

For each URL, the orientation (indegree and outdegree) and weight (weighted degree, weighted indegree, weighted outdegree) of the links (degree) have been calculated according to the implementation of the Gephi software. The ModularityClass community detection/qualification algorithm [BLON 08] was used to detect the communities of citations and classify the pages and nodes into citation communities. We also computed at the level of each domain the betweenness centrality and the local Page Rank [BRI 98]. The Page Rank is calculated only at the level of the sites present in the corpus. This allows us to know the strength of presence of a node at the heart of a network by calculating the probability of encountering this node when moving randomly in the network. Finally, Authority Rank, which allows us to evaluate and rank domains according to their authority in the network, and its corollary Hub Rank, which allows us to detect the domains of expression that play the role of infomediaries (or watchdogs) at the heart of the network by multiplying the links to a given community [KLE 99], allow us to calculate the authority of the nodes within constituted communities. Finally, closeness centrality calculations, and in particular harmonic closeness centrality [BRAN 01, BRAN 05], allow us to calculate the nodes that are at the heart of the network and best placed to meet the other nodes (calculation of the average distance to each node).<sup>7</sup>

We wanted to make the Network Actor Theory [LAT 07, LAT 10, LAT 14] operational at the level of digital media studies [BAR 17, BOU 16]. Finally, it is necessary to underline the rarity of the phenomenon of social resonance on the whole corpus. The measures of social resonance (likes, shares, comments, etc.) allow us to understand the reception of a unit of information. If we add up the structural analysis indicators of the citation network, we can build a multivariate influence scale that quantifies the notion of influence [JEN 16, ROS 17]. Added to the factor of position (who speaks, about what and on which device), we obtain three factors allowing us to study the strategies of actors at the heart of a digital sociology of controversies. The mapping of actors can then lead to studies of the "places" of influence of knowledge on the Internet by adding to a description of the positions taken, their social impact and their socialization environment.

The examination of web corpora containing health information shows an informational complexity and influence games specific to the structure of the web that contrast with the apparent ease of use of the search engine. In the study of our



corpus, the likes and shares of social networks all have a statistical distribution law in the form of a strong decreasing exponential (or Power law [BAR 14, BAR 15]). A hierarchy emerges from the library of documents, from the citation paths are revealed a determining maze of navigation, informal editorial communities show "small worlds" that are more or less endogenous. The Web is not a neutral list of links displayed on a search engine, it is a complex social informational architecture that determines the subjectivation of the reader. It then becomes necessary to couple the study of the corpus with that of the uses of this information by tracing the effective wanderings of the Internet users and the process of integration of these paths.

### **3.2.3. Qualitative approach: understanding the daily use of digital health care**

In parallel to the structural analysis of the web we propose a health information approach that completes the previous results with a longitudinal qualitative survey on online health practices, among a retired population, aged 60 to 80, using digital technologies. The choice of the qualitative method aims at understanding the health practices of elderly Internet users, both in terms of searching for connected information and in terms of self-medication, applied to the users themselves and to the people around them for whom they are doing the research. Although the choice of the population studied may seem surprising, it is ultimately relevant in the context of an approach to the digital health literacy of users. Indeed, this population, under the effect of biological aging, is particularly interested in the field of health and its management by the principle of self-evaluation [FOU 01]. It also presents complex forms of acculturation (digital, media and digital) [VIG 17], little studied in human sciences, in particular in French CIS. Risks in public health appear to be obvious, especially since health research online can lead to acts of self-medication, relatively well-controlled according to the capacities of access to relevant information (*ibid*).

Our qualitative approach sought to better understand the modalities of reception of digital information and communication technologies among the population studied, since "confrontation with the field is the condition for the perception of social practices" [MON 08]. In addition, it also seeks to study the implementation of the concept of digital health literacy in a population of users. The idea is then to verify the correlation between this appropriation and the development of good or bad online health practices, applied to oneself or to a third party.

Our qualitative approach includes two parts. The first is part of the project *Risque Informationnel Chez les Senior et Automédication* (RICSA), carried out by Bordeaux Montaigne University and the MAIF Foundation for Research and Risk Prevention in 2015 and 2016. The selected sample includes 31 seniors, interviewed in individual semi-directive interviews. The respondents are over sixty years old, selected according to multiple criteria: age, gender, place of living, standard of living, familiarity with digital technologies, etc. The sample was constituted according to a quota method, with a desire for equal distribution between the different criteria retained (age, place and standard of living, gender, former profession, social environment).

We deliberately chose to structure the sample on a principle of heterogeneity. We sought to diversify the contexts of online health use, in order to understand the convergent and divergent nature of the behaviors observed, as well as the complexity of the relationship to digital literacy. In addition, we felt it was important to understand "the complexity of the practices analyzed [through the investigation] of forms of knowledge other than that held by the researcher" [MON 08]. This approach seemed relevant to our approach. It allows us to encourage the emergence of concrete data that can contribute to the deepening and structuring of the concept of digital health literacy, without being too attached to a particular scientific paradigm. We then conducted a new wave of interviews in 2019, three years after the first phase, carried out with 30 of the participants of the RICSA project, using the same survey and analysis grid, with the same research objectives. Through this longitudinal study, we wish to verify the evolution of online health uses and, in particular, the evolution of the relationship to digital health literacy.

Concerning the analysis of the qualitative survey, we first chose the methodology of continuous thematic attribution, i.e. readings of the data seeking to invest, thanks to short expressions, the substance of the analyzed statement [PAI 08], in order to link it with the other data. This technique has the advantage of allowing a certain increase in generality of the field data. The thematic analysis "has as its essential function neither to interpret [...], nor to theorize [...], nor to bring out the essence of an experience", but "serves to identify and summarize the themes present in a corpus" [PAI 12].

We then proceeded to a categorical analysis of the content, in addition to the thematic analysis, based on the fact that "the aim [of content analysis is] to identify several categories [, which] will allow the researcher to classify and order the whole

corpus" [BAR 12]. This methodological contribution thus allows us to go beyond the relatively pragmatic thematic sorting, in order to bring the analysis closer to scientific exploitation of the data.

### **3.3. Key findings and issues in digital health literacy**

The results obtained allow for a better understanding of the state of the information on offer as well as the editorial issues that are at stake. The need to increase the skills of users appears all the more necessary.

#### **3.3.1. Strategic positions of health mediators**

In the study of the typology of speakers, we note that the discourse is dominated by health actors and journalists (2/3 of the sites). Patients and companies form the final third of the actors in this field. "Alternative" discourses<sup>8</sup> play a very minor role (about 1 or 2% of the sites). The most used communication platforms are editorial sites with a strong strategy of periodic contents (1st third), institutional presentation sites (2nd third) and then web 2.0 platforms such as social networks, forums and blog platforms (3rd third). This introductory description reveals very typical and fairly intuitive digital spaces. However, it is necessary to qualify this description for healthcare actors, because the associative form of healthcare practitioners generally aims to develop a strategy of information resource portals as much as an institutional strategy. And practitioners communicating individually have a social media strategy that is much closer to the patient than to their reference institution. Thus, the health information field seems to be distinguished according to three strategic factors: whether or not they are from the health world (32.5% of the sites), whether they are an organization (80% of the sites) or an individual (20%), and whether they belong to the commercial space (45.1% of the sites) or the public space (54.9% of the sites).

We then categorized the messages by a text mining method by automatically categorizing the contents according to an n-dimensional vector position. The main theme that forms the core of the representations aims to inform about the characteristics of the disease and the behaviors to adopt in a therapeutic educational approach (64% of the pages). This main theme is composed of 3 thematic axes. The

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<sup>8</sup>. We classify in this category all the actors who propose more or less global therapies based on non-scientific methods. Mainly methods based on the use of natural, magical or esoteric elements.

first concerns the description of the disease, its symptoms, its origins and its consequences (a large third of the pages), as well as a discourse of accompaniment and advice on how to live better with the disease and more precisely on the right gestures to live with one's disease (a second small third of the pages). A second thematic axis is a very emotionally charged discourse on the factors causing serious attacks and the serious risks incurred by asthmatic children (23% of pages). In addition, a third, more sensationalist axis occupies 10.5% of the positions, with themes as varied as the death of an infant with asthma in a hospital emergency room (a recurrent controversy that occupied 1.4% of the discourses in our corpus) as well as sensational studies on automobile pollution, intestinal bacteria, the presence of pets (dogs in particular) and drug interaction. Finally comes the promotion of spa treatments for asthmatics (2.7%) by companies in the health sector. Thus, nearly 80% of the pages studied are directly linked to a desire to inform the patient in a rather alarmist manner. A tiny minority are sensational pages that try to create a buzz through scoops.

Given the strong correlation of the variables *emitter\_type*, *media\_type* and *themes*, we operationalized the notion of *strategic position* by constructing an eponymous variable. The use of a new Hierarchical Ascending Classification (HAC) allowed us to build seven/eight strategic typologies in the corpus studied:

- The most important strategy, which occupies 2/10ths of the sites, strongly over-represents health institutions, public institutions, associations of practitioners and universities, and finally insurance and mutual insurance sites around the themes of therapeutic education and disease prevention policies. Here it is the institutional word that predominates.
- The second position (2/10ths of the sites) is that of the medical press and the specialized press, which use primarily editorial media to address therapeutic education topics, but with a high emotional value, such as serious crises and medical discoveries. This specialized press engages in the therapeutic education process, but through the filter of sensational information in a journalistic paradigm.
- We must add to this position one that is very close (competitive?), but more moderate in its treatment. This third position (1 / 10th of the sites), made up mainly of associations of practitioners, but also of a small part of the specialized professional medical press, endeavors to be the relay of current health information in order to live better as well as to prevent serious risks

and crises. This position, between that of health institutions and that of the medical and specialist press, does not prioritize information through the prism of the event. Many practitioners working in associations offer more general public information related to the concerns of patients and carers, based on the model of the advice they can provide in their practices.

- On the contrary, the fourth position (1/10th of the sites) is the one through which scandals arrive. Composed essentially by the general press using mainly editorial sites, these pages are clearly in search of scandal and accident and to a lesser extent of exceptional scientific discoveries which will attract audiences and sell well. We find here the archetype of the sensationalist press driven by a search for scoops whose contents are strongly propagated on social networks.
- The fifth position (2/10ths of the sites) represents invested individual discourse. Here we find the patient's discourse alongside the individual practitioner and a part of the alternativists (very marginal). They strongly invest in web 2.0 with a strong preference for blogs and social networks. Their favorite theme remains therapeutic education, a subject on which they challenge health institutions by addressing practices left on the margins of the medical profession. This category constitutes the active avant-garde of web 2.0, both expert and non-institutional.
- The 6th position (1/10th of the sites) is very close to the previous one and mainly involves patient associations, individual patients and the specialized press to a lesser extent. But this social group is that of conversations on forums. We find here the place of discourse that is very much studied in the sociology of the web, where patients and their carers are looking for practical advice in the daily management of the disease.
- Finally the 7th and last position (1/10th of the sites) is that of the commercial strategy of the companies which uses a very complete range of media on the basis of e-commerce sites, but also of portals and directories, institutional and thematic sites in order to sell products and related care services (cream and oils, thermal cures, etc.). A very complete communication strategy is then deployed on the basis of an institutional strategy of referencing and influence.

Thus, we must note that the actors occupy very distinctive positions, but that they remain within a traditional communicational order. Alternativists are, quantitatively, a negligible pinch in the discourse and do not appear (in our study

limited to the web seen by Google) likely to question the established order. The wave of patients' and patients' associations' discourse is very much in the minority compared to the presence of health professionals. The latter have been able to come out of their institutional reserve (individually or in association), by adopting the new socio-numerical media (collaborative websites, individual blogs, Facebook pages or groups, etc). However, the dominant players in health information remain the media industry through the general, specialized and medical press, which occupies the leading position in terms of speaking out in the field of health information.

### ***3.3.2. From medical legitimacy to editorial power***

To this sociotypical approach, we must add a performance analysis of the discourse. In our research on the influence of discourses on the Internet, we wanted to identify the social resonance of discourses through an accounting of likes, shares and comments on 2 networks (Facebook and LinkedIn). In terms of strategies, the strategies developed by the daily and regional press and the specialized press are the only ones that are clearly correlated with success on social networks. Conversely, health officials, practitioner associations, health bloggers and health forum are significantly underrepresented in the modalities of great success on Facebook. When we look in detail at the factors one by one in order to specify what weighs in the success of these strategies, we see that alternative bloggers are the only type of actor, far behind the general press, that can emerge from social networks. It is in fact the editorial strategy that provides the content necessary for social resonance. The difference in resonance between the press and the alternativists is due to the audience base on which the press relies.

However, the success of the alternative bloggers, considering the means they have, is still remarkable. If we add to these points, the analysis of the themes addressed, we discover that it is sensational information that significantly wins on social networks. Scandal such as the news of accidental deaths in a hospital is very clearly conducive to ignite social networks. Next in the ranking are articles based on "recent scientific studies" that make "exceptional" discoveries or the discovery of serious risk factors. It is thus very clearly the strategy of sensationalism of the press and that of the alternativists that emerge victorious from the social resonance measure. The medical discourse of therapeutic education and advice for a better daily life not only does not interest the press, but above all does not interest the social networks.

In our research, we included explicit citation in the body of the text as an indicator of legitimacy. We wanted to know if the nature of the actors played a role in their website's position in the editorial community. By cross-checking *actors* and *bin\_indegree* (being cited more than average) at the page level, we find that not only is the correlation significant [ $\chi^2(13, N=1245) = 47.8, p\text{-value} < 0.01$ ], but, according to Pearson's residual analysis, only individual practitioners (3.97), patient associations (3.68) and the medical press (2.78) are significantly over-represented in terms of their chances of being cited. On the other hand, no single topic was significantly more likely to be cited than another. The analysis of authority and page rank confirms the role of the medical press, but even more so that of associations of practitioners and health institutions at the heart of the citation network. Thus, the most legitimized actors in terms of citations are clearly those with institutionalized expertise in health, but in forms of intermediation that are more accessible than the official discourse. The medical press and associations of health practitioners enjoy a very powerful legitimacy in terms of co-citation in a context where individual initiatives seem to lack credibility. Institutional legitimacy and a therapeutic education strategy seem to be a source of influence with other web publishers. It is therefore necessary to be in a position of expert mediator in order to play an authoritative role on the web.

### ***3.3.3. A need for increased competence in information retrieval in the health sector***

The informational offer shows that it comes from a diversity of actors sometimes difficult to identify by the users, while the development of informational practices and digital skills in health on the web are far from being acquired. The results of the qualitative survey highlight a certain complexity of online health practices among the elderly population. The latter are particularly entrenched and have visibly increased over the years within our study sample, an evolution that can be considered the consequence of a triple effect:

The advancement of age, which goes hand in hand with the appearance of new symptoms and/or the aggravation of existing symptoms, in a more or less worrying way. The user may then be tempted to carry out a medical (self)consultation via the medium of the web, in order to assess the need to go to the doctor [VIG 17].

Online health uses tend to develop, especially with the appearance of new health platforms or platforms dedicated to teleconsultation. The Web thus tends, over the

years, to be related to the idea of self-evaluation [FOU 01] and to the taking charge of one's health.

The increase in the ease of use of digital platforms by seniors, due to the effect of usage mimicry (copying the uses of relatives and friends) and the intervention of descendants in the digital mediation [LED 12, LEDO 14] of uses and supports.

"The multiplication of Internet sites devoted to health raises the question of the quality of the information disseminated" [BOU 03], all the more so if we take into consideration the logics of crawling, of information classification, of marketing, influenced by the principle of attention economy, in particular in health matters [VIG 18]. Our analysis of the second part of the qualitative survey tends to show that, although health-related uses are more numerous, their effectiveness, quality and safety are no less problematic. Indeed, the groups presenting risky practices in the first part (alternative self-medication, health-seeking without medical skills or knowledge, refusal to use professionals, etc.) do not show an increase in their skills. Beyond this notion of research, it appears that the refusal of chemical medication and of health monitoring by a professional have, in this group of about ten people, been largely affirmed.

Christiane, for example, who in 2016 refused the vaccine and did not always follow her doctor's prescriptions, has completely stopped consulting health professionals in cases of acute symptoms or seasonal pathology. Since the end of 2018, she has only resorted to online searches, even though she has a high-risk profile and believes herself that her health has relatively deteriorated in two years. She combines a very low health culture with a research methodology based on a certain associative serendipity, with decision-making for herself and for third parties that can lead to dramatic effects. In 2016, she had indeed recommended an ointment to her husband, following a search on health forums, the application of which could have had lethal consequences due to drug interactions.

However, since then, her online health research skills do not seem to have evolved and her rejection of institutional discourse has increased. For example, her research methodology relies on health information published on forums, without medical terminology, and other sites whose information is not verified. Christiane's case illustrates the fact that evaluating information is "an operation mobilizing both our knowledge, our skills, but also our personal values, our judgments, our opinions, our tastes. This operation is neither purely technical, nor purely documentary, nor is it purely cognitive, but it intertwines all these dimensions and many more personal



ones. [...] The evaluation of the credibility of an author, a text or a piece of information was already a challenging task in the printed world, but it has become much more complicated in the digital world" [SER 12]. The complexity, for this type of profile, is based on multiple difficulties. For one, there are gaps in information research (identification of sources on search platforms and verification of the relevance of information). Furthermore, the health culture and the relationship with the medical field lead to a relatively high risk (lack of vocabulary, interpretation of symptoms, presumed credibility of authors without verification, etc.). Finally, the consideration of commercial and attentional logics seems to be weak, users having little awareness of the marketing dimension linked to the results of health research on the Internet.

One of the main difficulties of the users interviewed is based on the "undifferentiation of sources" when searching for health information online, as well as a "general blurring of sources and status of documents" [SER 12]. On the net, it is much less easy for them to sort out between deleterious, commercial or safe information. In addition to this, there are the editorial processes, with the necessary distance between the form of the document and its content. A well-written text, using medical terminology, does not guarantee its scientific and medical relevance, but plays on the notion of credibility by using emphasis and scientific rhetoric. Here we see the link between traditional information literacy and info-digital literacy. Research on the Web thus depends on classical skills and new informational skills, taking into account the specificities of the digital medium, as well as the personality and general culture of the users. However, this intermingling does not seem to be taken into account by the retired users in the sample. "The development of intellectual technologies of representation and access to information is making the phenomenon of serendipity a more important part of research every day" [ERT 03]. Serendipity does not depend so much on the health literacy of users, but rather on their digital literacy and its application to informational research. Thus, if users are able to analyze health information, they experience difficulties in finding it on search engines.

If they avoid open forums and prefer institutional sites, they acknowledge having difficulties in identifying the relevance and legitimacy of third-party sources, particularly those of pure-players dedicated to health. "In the digital world, and even more so on the Internet, we are confronted with a mixture of genres and documentary supports, with the appearance of forms and documentary supports specific to the Internet, [...] without equivalents in the printed world" [SER 12].

Online health research thus presupposes a specific culture, which the elderly are not always equally endowed with. Thus, their health research takes the form of a certain informational browsing, in which users consult a relatively wide variety of sources, while calling upon their health literacy to perform informational sorting. To use Ertzscheid and Gallezot's image, users are looking for the needle in the haystack, without presenting a structured research methodology adapted to the digital medium, despite their level of health literacy.

Thus, the research methodology consists of "randomly locating [...] new keywords, new names of people [or Internet sites] that will lead to another line of research and will constitute an answer/solution to the question/problem" [ERT 03], thus resorting to associative serendipity. Information browsing mobilizes little or no health knowledge and skills. Or at least, the medical and media background of this user profile does not seem sufficient to guarantee a legitimate and relevant result. Within the sample, seniors who use associative serendipity have never worked in the medical field and are interested in this field more as a hobby than as an advanced specialization. The impression of great quantities of information - even of infobesity - then acts as an element that satiates the informational appetite, without the results and their interpretation being consistent with the user's initial need. "In this process, the information will be primarily "captured" by the user and will be used as a basis for the associations that he will build in order to complete his quest" [ERT 03]. However, what good is such an association if health literacy does not allow for a justified and relevant analysis of the information - information which itself tends not to be based on a structured approach adapted to the challenges of attention capture?

Moreover, the risk of such health uses, combined with the "serendipitous" nature of online searches, relies on the subject's ability to see himself as an object. "By becoming a doctor of oneself, we must study the constitution of the subject as an object for itself, the disease becoming an object of verification and control of oneself by oneself" [AND 10]. Searching for health information online, for oneself or for others, presupposes a necessary distancing and stepping back on the part of the user, so as not to fall into emotion or subjectivity. It is therefore essential that this same user has the skills and knowledge to enable him/her to objectify the results of his/her research. This applies as much to the informational dimension of research (relevance of the sources used, etc.) as to the health dimension (identifying the disease linked to the symptom or pathology) and to the media dimension (getting rid of the commercial aspect of certain information).

### **3.4. Health, information and digital technology: a logic in line with transliteracy**

Between understanding the informational offer on the Internet and analyzing patients' health literacy, our research highlights the need to use the notion of transliteracy [THO 07, LED 14] in the analysis of health information on the Internet. Literacies depend on an alliance between:

- Information literacy: searching, finding, analyzing and reusing information, etc.
- Digital literacy: using a search engine, knowing how to classify information, detecting fraudulent and commercial information, identifying relevant sources to verify, etc.
- Health literacy: identifying a symptom, handling a dosage, checking for contraindications and drug interactions, etc.

As the informational and technical context has evolved, health literacy cannot remain at the same stage as it was at the beginning. In this respect, it is impacted in the same way as other information and media literacies, under the effect of the evolution of the information on offer. In this context, the user or patient becomes a co-producer of potential information. From the opinion mentioned on a platform, to the active participation in communities of patients with chronic diseases, the place of users in health information processes has evolved quite clearly. Nevertheless, this communicative logic shows differences in users' mastery and skills. These differences are in addition to the initial difficulties of health literacy, with regrettable skill deficits in the ability to search for information, but also difficulties in understanding dosage and its application.

#### **3.4.1. An extension of competences to be put into context**

This evolution makes the analysis of users' skills in the field more complex, as the evaluation of an individual's abilities cannot be based on the same criteria as in the 1980s. In this respect, health literacy meets the same concerns as media literacy and information literacy, which have been strongly impacted by the development of new media, by the possibilities for users to produce information and by access to new types of information on a variety of media. Consequently, health literacy cannot be understood without digital media. This is why we have proposed to redefine it as

digital health literacy, as computerized or digitized processes interfere with medical activities and patients' practices.

This choice has also been expressed at the level of the European Union, which has financed projects dedicated to digital health literacy in order to improve the level of European citizens. One of the tracks explored is producing online MOOCs in order to develop the empowerment of European citizens<sup>9</sup>. If the diagnosis seems relevant, the MOOC approach seems to be a questionable reading, as the skills mentioned and described above depend on a strongly prevailing economic, social and cultural context. It is the first stumbling block of a complex literacy, which mixes informational and digital issues with health skills, that we are tempted to neglect the context in an approach that would privilege entry by a series of skills.

However, the literature on health literacy has always emphasized the importance of context. Research has often focused on socially disadvantaged populations to better understand where the key issues lie. In this context, the research shows that there are often great difficulties in understanding the organization of the health system and that vocabulary difficulties far outweigh the desire to make queries on a search engine. Indeed, the specific vocabulary of health professionals, coupled with those of medical services, is sometimes difficult to understand for patients, especially since the public may be allophone or even illiterate.

Several studies have examined methods of assessing health literacy [BAK 99, PAR 95]. Various tools have been developed for this purpose, in particular to highlight training gaps and deficits that are more or less worrying depending on the populations studied. These tools include the Rapid Estimate of Adult Literacy in Medicine (REALM) and the Test of Functional Health Literacy in Adults (TOFHLA). Assessment methods are often based on questionnaires, which can be used at the national level. It seems appropriate to focus on the Health Literacy Questionnaire (HLQ), developed in Australia, which has been adapted internationally. It has been translated and adapted into French [DEB 18]. The questionnaire allows a variety of issues to be addressed. Nine of them are highlighted:

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<sup>9</sup>. This is the case of the Ic-Health project (Improving Digital health literacy in Europe), whose real contributions are slow to be seen. <https://ichealth.eu/>

- Having a good relationship with health care providers
- Having enough information to manage my health
- Actively managing my health
- Receiving social and family support for health
- Ability to evaluate and assess health information
- Ability to actively engage with health care providers
- Knowing how to find your way around the health care system
- Finding the right health information
- Understanding the medical information well enough to know what to do

The objective of the questionnaire is to be able to identify avenues of support and remediation for users. With several colleagues [BAT 14], Richard Osborne has developed a dedicated approach for this purpose: OPTimising HEalth LIteracy and Access (OPHELIA).

### **3.4.2. A transliteracy to be modeled**

Consequently, digital health literacy is in line with observations already made regarding the need for training in digital and information literacy. It cannot really develop properly without basic literacy and social conditions that truly allow the user to make informed choices with a free conscience. To face the impression of an elite literacy, which intersects hybrid competences, it is possible to consider the track of transliteracy as opportune. In Sue Thomas and her colleagues' definition, it appeared as: "Transliteracy is the ability to read, write and interact across a range of platforms, tools and media from signing and orality through handwriting, print, TV, radio and film, to digital social networks" [THO 07].

Transliteracy should therefore be understood as cumulative literacy, building on the knowledge and skills that users have acquired in other circumstances and that can be reinvested. This aspect appears essential as a response to the idea of producing MOOCs that could be addressed to all types of audiences. This is the second lesson. It is not possible to hope to increase the level of digital health literacy without having educational systems that provide an excellent level of information and media literacy, as well as a good level of digital literacy. At the same time, quality training in health information is essential to ensure that people do not have

difficulty understanding not only the health care system, but also basic anatomical knowledge, without which self-awareness is severely lacking.

### **3.4.3. Data literacy: a new perspective**

A fourth sector is now developing with regard to digital health literacy: the issue of health data. There is a potential reversal of perspective with the fact that the production of health information by users and patients has become an object of covetousness that adds to an informational offer on the web already highly prized by commercial sites. Connected objects and associated services allow the production of personal health data in addition to those already produced by official services. This personal health data includes data contained in medical records, such as the shared medical record (DMP), as well as data retrieved by connected devices prescribed or used autonomously, to which can be added all the data from searches for information on search engines, consultation histories, as well as consultations and registrations on forums that deal with health information.

While the summary typology outlined here gives the impression of separate silos, doubts may nevertheless be raised, including in Europe, where the stakes of takeover and recovery are of concern, especially since they involve a series of actors who have been somewhat on the sidelines until now<sup>10</sup>. Subsequent reuse, unforeseen or insufficiently described, as well as contracts for use, leave the door open to potential decisions that could be taken by insurance companies and mutual insurance companies or other actors. Even the organizations that make it possible to establish DNA and possible ancestry, which target their advertising on the question of origins, are nevertheless building up databases with considerable medical potential.

Current works on data literacy [KOL 15] question, on the one hand, the stakes in terms of training in order to have advanced workers who meet the requirements of a working world, and seek to identify, on the other hand, the means of exercising a citizen's view of the data made available by open data. As a result, the issue of personal health data raises issues of paramount importance, which cannot be resolved by a few legislative safeguards and a simple desire for empowerment [LAB 19]. Ultimately, the data component of digital health literacy could be the element that highlights the strong inequality that exists between citizens, with mechanisms

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<sup>10</sup>. One example is the fact that Boris Johnson's government in England has granted Amazon access to medical information stored on NHS (National Health Service) servers.

that could lead to a divide between those able to retain forms of control over their data and those forced to make it available to third parties in order to benefit from seemingly less costly services.

### 3.5. Conclusion

The first phase of the study highlighted several original findings. This quantitative approach aimed to map and analyze the architecture of health information available on the Web through the example of asthma in children. The strategic positions of the influencers are sufficiently typified to be able to speak of a digital microcosm. The press and health professionals remain the dominant players in health information on the Internet with more than 70% of the pages produced. Opposite them, the patient's voice is in the minority (14%). Even if the press is constantly looking for sensational information, novelties and unusual facts following a logic of "breaking news" and ratings, there is both a specialization and a hierarchization in the strategies of the actors that emanate from the editorialization of sensational and exceptional information to therapeutic education mediated by health professionals. The core of the network in terms of influence remains a hierarchical three-way game between the medical press, practitioners' associations and health institutions. The discussion of the intimate and daily concerns of the patient and the commercial aspect of health remain very weak in the digital public space studied.

If we add the very weak presence of the alternativists (less than 3% of the pages accessible in the search engines) to the corpus, we have to admit that the social order of the health information discourse is very little challenged in the digital era. Both in terms of quantity (content, sites, etc.) and in terms of web influence. However, we feel the presence of highly specialized information content in the context of discussions on daily life associated with web 2.0. As we have said, the need for research on the mediated web within social networks appears essential to properly measure this phenomenon.

The constantly debated definition of digital health literacy shows the difficulty of giving a good assessment of it. There are a few health literacy indicators that now incorporate informational and digital issues [OSB 13]. While they may be interesting and timely at a given moment, the indicators require updating, which ultimately makes it difficult to carry out long-term monitoring, or even to claim to obtain improved results, since the territory of this literacy continues to become more

complex as time goes by. It is therefore impossible to think of it too separately from the other literacies. A few years ago, we tried to produce a digital health literacy indicator with an online test<sup>11</sup>. This tool mixed basic health and dosage questions with informational and digital questions. It should be revised by integrating the relationship with connected objects and data. The results of the test showed a strong deficit in the understanding of the functioning of search engines, particularly concerning the methods of ranking results. This lack of algorithmic understanding already showed the need for search engine literacy [LED 16, LED 17], which is now coupled with the issues of personal data and possible automated processing. This complexity raises questions about training issues as well as about survey and analysis methods, which are forcing public health fields to be more and more open to hybrid methods and transdisciplinary associations. Presumably, this also leaves the door open to the possibility of anthropological work, which integrates these different findings to propose services that do not leave the responsibility of training solely to users and patients.

Nevertheless, even in this framework, as a complement to this study, we would have to conduct comparative studies on the corpora accessible on the web (including social networks) against the browsing data of a cohort of users to be able to consolidate our results by comparison. But only future developments of our project (allowing a close crawl of relevant documents with respect to a dictionary *a priori*) would allow us to introduce a real snowball sampling. It is on this condition that we could free ourselves from the framing wanted by the search engines to draw a more representative web architecture. We could then study the effect of this architecture as public health factors influencing the health literacy of a cohort of patients.

Questioning health literacy challenged by digital technology forces us to rethink training strategies in this area in order to respond to increasingly important issues at both the individual and collective levels. The identification of competencies certainly appears useful, but history shows that this hybrid literacy refers to clearly elitist levels of competence, if one seeks to reach a minimum level. The will to make the citizen become more competent seems commendable, provided that training and its articulation are rethought. But it cannot be enough, as the conditions in which it is exercised vary from reading a dosage to querying a search engine, via connected devices. Above all, it seems appropriate to advocate for a strengthening of mediation mechanisms. In the short term, this implies better training for healthcare

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<sup>11</sup>. Digital Health Literacy Placement Test:  
<http://www.megatopie.info/testor/enquete.html?e=19>



professionals in these issues, but also the recruitment of intermediate professionals capable of performing this mediation. Indeed, it should not be forgotten that this is not only a series of skills to be mobilized and exercised, but also a form of social, cultural and civic mediation.

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