

## **Do we trust and are we empowered by “Dr. Google”? Older Spaniards’ uses and views of digital healthcare communication.**

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Keywords: health, the elderly, trust, empowerment

Highlights:

- Focus group participants who look for information online were found to apply appropriate criteria to differentiate its reliability in general terms.
- None of the participants mentioned or seemed to know whether there were official criteria to give guarantees of the reliability of the information. Nor were they aware of the possibility that some healthcare institutions may use their websites to “sell” certain therapies or drugs.
- Online healthcare information is giving older people the chance to take more responsibility for their own health and, when well founded and well used, it can act as part of a safety net that complements the work of healthcare professionals.
- Being able to compare and contrast the information received from one’s physician is in itself an empowering development.
- Seniors’ use of online health information shows a nuanced understanding of its uses, seeing its value but also registering its potential for fostering “cyberchondriasm”.

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### **Abstract**

By 2050, 34.5 percent of Spaniards will be over the age of 65, making Spain’s population the third oldest in the world. Ageing populations present numerous challenges and opportunities and these are particularly apparent in the area of healthcare and health communication. Longer life expectancy pushes greater demand for information regarding health and healthcare institutions are exploring ways of meeting these demands in an effective and efficient manner. This study listens to the voices of older people themselves, exploring seniors’ use of digital communication to find information related to health and healthy living. Part of a wider project examining the use of digital health communication for active ageing by Spanish health institutions, this research used focus groups to explore the extent to which older people trust and feel empowered by digital media in finding about health issues. It found that online healthcare information is giving older people the chance to take more responsibility for their own health and, when well founded and well used, it can act as part of a safety net

that complements the work of healthcare professionals. Being able to compare and contrast the information received from one's physician is in itself an empowering development.

## **1. Introduction**

By 2050, 34.5 percent of Spaniards will be over the age of 65, making Spain's population the third oldest in the world after Japan (36.5 percent) and South Korea (34.9 percent) [UN, 2014] (Auni3n Vald3s, 2014). This fact about Spain – the increasing demographic weight of the elderly in its population – is similar to that of most first world countries and Spain is facing the same challenges for its infrastructure and its use of resources.

The challenges and opportunities posed by the ageing of the population are particularly clear in the area of health. Longer life expectancy, sometimes accompanied in older people by chronic illnesses such as diabetes and high blood pressure, drives an ever-greater demand for information regarding health. People seek more information and communication on health, particularly about the prevention of disease and the promotion of healthy lifestyles. At the same time, the education of the patient about the importance of his/her participation in caring for his/her own health has become a main focus for healthcare institutions, leading to the need for more effective communication among all the actors involved.

For older people, healthcare information and communication are often an urgent need. However, "the centrality of communication in the studies of ageing is not yet well established" (Nussbaum & Coupland, 2008, p. xi). There is very little research on the attitudes, perceptions, beliefs, fears and hopes of older people regarding how to obtain healthcare information on the Internet.

This study examines the relationship seniors have with digital healthcare communication. Do they use the Internet for healthcare issues? Do they trust the information they find? Does this provide a degree of empowerment understood as the process and mechanisms through which people take control of their lives (see Silva & Mart3nez, 2004)?

## **2. Research design**

The study is part of a multi-method research project which, after a thorough literature review of research regarding digital healthcare communication and seniors,

has sought to examine the views of health professionals and of older members of the population in relation to digital health communication. The research team first carried out a series of in-depth interviews with healthcare professionals in Madrid and Navarre, exploring their strategies for digital communication in general and, in particular, their strategies for addressing older people online (see Sánchez-Valle, Sanders & Torrecillas, 2013; Sanders & Sánchez-Valle, 2014).<sup>1</sup>

In order to understand the views and attitudes of older members of the population, researchers decided to study the first-hand experience of potential Internet users between the ages of 56 and 75. They organized three focus groups made up of both retired and employed men and women of these ages who resided in the Community of Madrid and the Community of Castilla-La Mancha.

As Yin (2012: 7-9) points out, qualitative research has the advantage of studying the meaning of people's lives in relation to their viewpoints, their "voices," through which they express what they wish to say instead of being led towards certain answers through questionnaires and surveys. It also means that attention can be paid to the full value of the contextual conditions rather than being limited by a certain number of variables to be studied. The focus groups allowed researchers to hear the voices and opinions of seniors as regards their use of and, chiefly, their use of Internet for health issues. The groups also allowed for an efficient use of resources, allowing researchers to collect rich data in a time and cost effective way.

Although the participants in the groups shared a similar demographic profile (between 56 and 73 years old), each of the three groups had a different socio-economic and gender profile. This variety offers a richer set of viewpoints and voices than would have been possible in groups formed without mixed gender characteristics or with the same socio-economic profile.

Group A was composed of four women and two men. They are all retired; the youngest was 63 and the eldest 70. Their profile, defined by their past employment, is that of lower grade managers and professionals, and lower grade supervisors and technicians.<sup>2</sup> They had met at French classes for adults in the city of Guadalajara, an industrial and commuter town close to Madrid, with a population of about 83,000.

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<sup>2</sup> The classification follows the European Socio-Economic Classification -ESEC. See [http://cordis.europa.eu/result/rcn/88390\\_es.html](http://cordis.europa.eu/result/rcn/88390_es.html).

Group B was made up of three men and three women. They are all retired or had taken early retirement, are aged between 55 and 70, and have the same professional profile as the previous group. They are all Internet users and live in Paracuellos del Jarama, a town located in the Autonomous Community of Madrid with a population of about 21,000.

Group C was made up of five women, all of whom were retired except one who was unemployed. The youngest was 56 and the eldest 81. They had all worked in service occupations or were unskilled workers. They know each other as they all reside in the same neighborhood, Chamberí, which is a neighborhood in the centre of Madrid with 250,000 inhabitants with very mixed socio-economic profiles. As the Madrid Town Council states: “Marked ageing of the population is common in the whole district (on 1/1/2003, 23.41 percent of the population was over 65)” (2006, p. 108).

The focus group moderators ensured that, with minimal interference from them, all the participants could express their opinion on their use of digital technology in general and, in particular, on their use of the Internet for health matters. The aim was to obtain the groups’ opinions on how useful and trustworthy the Internet is and whether or not it acts to empower older people with regard to health issues.

The moderators guided the group discussions towards two main subjects. First, the focus group participants explored their relationship with digital communication in general. They discussed how often they use it: daily? Weekly? For how long? Which platforms do they use? Why? Second, they explored their use of digital communication for health matters. In this part of the discussion, issues were explored regarding the participants’ perceptions, feelings and attitudes in relation to the Internet and health. Researchers were interested in understanding what participants considered useful, trustworthy or non-trustworthy as regards health issues in the digital area. They also wanted to know if the uses of the Internet made the participants feel more independent or not. What advantages or disadvantages were there in using the Internet for health matters? The group meetings lasted approximately an hour and were recorded and later transcribed to facilitate analysis. Through an analysis of qualitative content, the research team identified key issues recurring in the groups, together with differences between both the groups and between individuals as will be seen below.

## **2. The Internet, health and older people**

The availability of the Internet and of Web 2.0 (which has now become the new, more interactive and bidirectional model 3.0), on laptops, *iPads*, wi-fi devices and, particularly, smart phones, as well as the development of apps with a huge variety of applications contributing to social and economic change, not least in the healthcare environment. Research into healthcare communication has been ongoing for 50 years (Thompson et al, 2011, p. xiii) and has focused on two main areas: first, external communication including health campaigns and specifically the use of information technology to improve communication management; second, interpersonal communication, particularly between healthcare professionals and patients (Wright et al., 2013).

Online health communication is a growing research area where changes are being seen in improved *distribution* of and *access* to healthcare information and also in the facilitation of communication between healthcare worker and healthcare worker, healthcare worker and patient, and patient and patient. The distribution and access to information and the impact on healthcare relationships, and their concomitant effects on treatment outcomes and costs, are, then, two fundamental lines of inquiry in healthcare research and practice.

At present, the possibilities for obtaining health information online are immense. The number of healthcare websites has grown exponentially in the last few years. According to data from the Spanish National Observatory of Telecommunications and the Information Society (*Observatorio Nacional de las Telecomunicaciones y la Sociedad de la Información-ONTSI*), over 30 percent of Spanish Internet users have searched for health information online in the previous week and 36.2 percent in the previous month (ONTSI, 2012). As a result of the growth in use, the need to ensure accuracy, independence and quality content is also an issue attracting research interest.

In Spain, studies have focused on the analysis of health campaigns (Cuesta Cambra et al, 2008), on the digital area (Cuesta Cambra, 2012; Lupiañez Villanueva, 2011) and, particularly, on the use, reliability and accessibility of the websites of Spanish healthcare institutions (Arencibia-Jiménez & Albar-Remón, 2007; Doblaz Arrebola, 2008; Conesa Fuentes & Aguinaga Ontoso, 2009; Conesa Fuentes, Aguinaga Ontoso & Hernández Morante, 2011). Cuesta Cambra (2012) has also examined the changes produced in the area of information technology and health from a psychosocial perspective.

Some studies have focused on analyzing the problems the seniors have in accessing the Internet (Jiménez Pernet, García Gutiérrez, Martín Jiménez, & Bermúdez Tamayo, 2007), and on the obstacles in accessing and understanding the information on health that appears on websites such as, for example, the requirement for a high reading level needed to understand health information (Bernald et al., 2001; Blanco Pérez & Gutiérrez Couto, 2002). The quality of the websites (San Norberto, Taylor, Salvador, Revilla, Merino & Vaquero, 2011; Lupiañez Villanueva, 2011; Rancaño García, Rodrigo Pendás, Villa Estébanez, Andelsater Fayad, Díaz Pérez & Álvarez García, 2003; Berland et al., 2001) is another of the subjects that has attracted the attention of researchers.

The Spanish National Observatory (ONTSI) has carried out research concerning the use of the Internet among all age groups including older people (INE, 2012) and in particular regarding the development of e-health (ONTSI, 2012). This organization found that one of the main obstacles to the use of the Internet as a source of information is not knowing whether the information is reliable (54.4 percent of those surveyed) and the risk of misinterpretation of the information obtained (28.7 percent of those surveyed), together with the fact that the level of knowledge of eHealth resources among people with an average age of 64 is much lower than among younger population groups.

Other institutions (Pfizer & Cocktail Analysis, 2010) discovered that among Internet users the Internet is the main channel for information and consultation on health issues, with 80 percent usage compared to other more conventional channels such as visiting a physician (77 percent) or consulting a pharmacist (46 percent), although the research also indicates that the Internet has become a complementary information channel as patients turn to it before and after visiting a doctor.

Studies have been carried out to assess the quality of medical information on the Internet and to identify the potentially harmful effects that poor information quality or the misuse of health information may have on users. The European Union is developing several research projects such as MedCIRCLE that offer tools and filters to assist Internet users in assessing the quality of health information (Mayer, Álvarez, Santos & Leis, 2004).

Regarding the credibility of the information on the Internet, studies such as that of Llinás, Mira, Pérez-Jover and Tomás (2005) have identified the criteria that make the websites more credible and conclude that the perception of the quality of a website is

not only affected by its content but also by its design. Studies by Eysenbach and Köhler (2002) and Mira et al. (2004) have found that the credibility given to websites is high and this can affect the expectations and decisions of patients. Eysenbach and Köhler (2002) found that trust is generated chiefly by the source of information (healthcare institutions' webpages, for example), technical but easily understandable language with scientific references and, less importantly, issues related to accessibility and ease of use (the presence of a site map, search facilities, fast interface and a contact email address for the webmaster, for example).

Research by López Hidalgo, Aguado Gómez, Sánchez Ruiz, García-Moreno Rodríguez and Alejandro Lázaro (2010) focuses on the study of the design of websites and their relationship with the level of trust the user feels towards the information she/he finds. The study by Kunst, Groot, Latthe, Latthe and Khan (2002) came to the conclusion that websites that look credible do not necessarily offer high levels of reliability while Rosenvinge, Laugerud and Hjortdahl (2003) showed that the updating of websites is a source of trust as is the involvement of healthcare professionals in the websites.

In general, the studies carried out on the use of the Internet in relation to health information have used quantitative research approaches and have focused on the study of the Internet from the *source's* perspective. The *user's* point of view, particularly that of older users, has been less visible in research. The researchers have found that only a few studies aimed to listen to the voices of seniors telling their digital stories in their own words.

This is the aim of this study: to reflect the opinions of older people regarding health information available online. The researchers have adopted a culturalist theoretical approach, which seeks to understand how people interpret the context and content of their social experience and how they perceive the meaning of this experience. This approach is also complemented by attention to structural factors, social facts such as age, sex, education and income that influence people's behavior and can be decisive for their opinions and behavior.

#### **4. Results and discussion**

The focus group participants, particularly from groups A and B, were often in agreement on many subjects regarding their use, attitudes, emotions and perceptions of

the Internet in general and, specifically, its use for healthcare ends. Groups A and B were made up of men and women with a middle-class socio-economic profile. Several participants in group C, made up of women only with a lower socio-economic profile, had never used the Internet, but this did not stop them from expressing their emotions and attitudes towards this medium and its usefulness, or lack of usefulness, for healthcare ends.

What follows is a summary of the very lively discussions of the three groups, and underline the points on which they agree or disagree about the Internet, how they use it for healthcare matters, if they trust it, what advantages and disadvantages they see and, finally, if they believe it to be a source of greater independence and empowerment.

#### **4.1 Use of the Internet in general and as a source of healthcare information**

In groups A and B, all the participants except one use the Internet very frequently: every day. The person who does not use it confessed that: “Maybe due to laziness, I don’t know, because I think I don’t really need it, while she is here [participant refers to his wife].” The attitude of almost all the participants towards the Internet was correctly summarized by one of them: “but, listen, Internet and I are almost sweethearts.” The uses most frequently mentioned by the two groups were to read the press; to keep in contact with family members who are away; to listen to music; to find information about recipes, hotels and maps, and to send email and WhatsApp messages. They access the Internet most frequently on their smartphones and devices like the iPad and tablets, and are dedicated users of WhatsApp (“almost always WhatsApp,” says one of the participants) and Facebook. Some of them use Skype and Spotify but none of them uses Twitter: several people had no idea what it was for.

Among the participants who used the Internet the least, several (all women) stated that they were a little afraid of it. One of the women in group B said, “If I don’t use (the) Internet more it’s because I’m chicken, I’m afraid of being attacked by 300 Trojans, which did happen to me once.” Another from group C said, “Yes, they have said to me, 'Do you want it, mum?' but it’s very complicated.” A fellow group member stated, “I use it but it’s not part of my life. I can live perfectly well without it. I prefer to have a real group of friends.” One woman blamed her lack of Internet use on her husband: “If Miguel was interested in it, but Miguel isn’t either. I say, 'Let’s buy a computer' and he says, 'What do we want one for?' He hasn’t even learned to read messages on the cell phone.”

Almost all of those who use the Internet acknowledge that they use it regularly for health issues. Several people ask for medical appointments using the Internet. Two people considered that it was particularly useful to receive messages to remind them of appointments with the doctor which they had made a long time before: “The outpatients’ clinic, when you have an appointment which was made a long time ago, sends you a message a few days before.”

One use mentioned frequently by group participants is the search for information to complement that given by their healthcare professionals. One participant went so far as to say, “You find out more on Google than from the doctor.” This search for complementary information is, to a certain extent, because of not understanding medical jargon. As one participant in group B said, “Often the doctor says four things and leaves it like that, and if you ask him for an explanation it’s even more confusing.” Another participant was of the opinion that the Internet provided another point of view. “What happens is that before, for a second opinion, in general, particularly about serious illnesses, we used to go to another doctor and again to another one, we went to two or three doctors. And well now, maybe, if we have any little thing wrong, we’ll go on the Internet to find out a little about it.”

Consulting the Internet also is seen as a means of discovering potential therapies for health problems. For one participant in group A the Internet is, “like a medical encyclopedia” that someone can consult about any doubts they have regarding healthy habits or advice on illnesses that already have been diagnosed. One participant talked about her interest in non-traditional medicine and others commented that they had looked on the Internet for references about the healthcare professionals that attend them or who would do so in the future. “Just imagine, you go to your doctor and you have something specific that has to be seen by a specialist. Being able to see what he’s like, that is, going on the Internet and having references about him...” Using the Internet to find out about a doctor’s experience and career is also beginning to be applied to information on medical centers and hospitals.

However, for one participant, “The Internet will never, ever, take the place of a physician. Maybe in the future...” But another participant from group B answered this statement categorically: “It depends on who the doctor is and who the patient is.” As regards the ways most frequently used to access information on the Internet, all of the participants use the search engines Google or Wikipedia more than any others. One

of the participants said that he consults information in the health sections of the online versions of general newspapers.

The participants who said they did not look for health information on the Internet gave two reasons. First, they said that they preferred to consult the physicians in person. The second reason given was because they had no illnesses, but this explanation also implied being somewhat nervous about encouraging hypochondria. One participant explained that he did not look for healthcare information online "...because I am not interested in illness. I don't like it because if you see a symptom you may say to yourself: Oh! I think I have that too!"

#### **4.2 Advantages and disadvantages of Internet for health information**

Almost all the participants agree that it is very useful to have health information on the Internet and that it offers an abundance of reasonable information. However this very abundance is also seen as a disadvantage. As one woman said, "When you read a lot, one person says one thing, another says another thing and in the end we don't know where we are". There is also a certain amount of fear about the misinformation that may exist on the Internet and the possibility of misunderstanding what is there, which may cause concern about one's own health or that of friends or family members. In the words of one participant, "Sometimes, if you're looking at a certain pathology, the Internet may muddle things up, and it may tell you something that you may follow." One person even thought that wanting to find health information on the Internet could "turn your life into an illness."

And there is another disadvantage mentioned by several people, both users and non-users of the Internet, which may have to do with the participants' time of life. Some of them are in the older age range and others getting close to or already in old age. The idea is that they prefer to spend the time that is left to them with people rather than with machines. "Although it is very useful," one participant said about the Internet, she added that, "at our age and looking ahead, we prefer to enjoy things in the flesh rather than sit in front of a communication medium." The architecture of websites also causes problems in accessing the information for some people. One participant said, "When I see something strange, I turn to the print versions of the medical dictionaries I have; it's much more practical and simpler because otherwise you go crazy searching back and forward. That's the problem with the paging on these screen things..."

### **4.3 Confidence and distrust in the use of the Internet for healthcare information**

Except for the declaration of one participant that: “You can’t trust it [the Internet on health issues],” in general, the participants were clear that it all depends on the credibility of the sender and the information. Several people stated that it was essential to apply logical criteria in order to judge the reliability of Internet sources. They mentioned several habits that they recommend in order to test the reliability of information on digital platforms, particularly of healthcare information. They include practices such as comparing the information from different sources and finding trustworthy dependable sources. As one woman said, “You can go to specialist professors on the subject, who have given conferences, who have given talks that you can find on the Internet. In other words, we’re not talking about Wikipedia.” Some of the older Internet users realize that not everyone who puts information on the Internet is to be trusted or that all information on the Internet is reliable. “There are a lot of wise guys,” said one of the participants. Several people voiced their particular mistrust of blogs and chats on health issues.

On the other hand, the attractive design of websites and their readability were pointed out as being influential in how reliable seniors feel a website is, but above all, the source is the main basis for credibility.

### **4.4 Empowerment of older people**

How did the participants see the impact of the Internet in general and in particular regarding healthcare information on their independence, on their degree of autonomy? Many of them felt a certain amount of ambiguity about the Internet in general. Even though almost all of them recognized its potential to give information, to connect them with people and to have fun, one participant in group A expressed an opinion about the Internet that was shared by several others: “What I don’t like is that I think it deprives us, sometimes, it takes away our freedom. For example, with WhatsApp and email, that someone sends you a message on WhatsApp and you have to answer, otherwise...” Several people commented that they didn’t want to be obsessed with the Internet, something they see in the younger generations. “What I don’t want is to be absorbed by it,” one person said. Another non-user from group C had a very critical perspective of how digital media take over people’s lives: “In the street, they don’t have conversations. None at all. They don’t write, they don’t talk to each other, nothing like that, they spend the whole day messaging and using WhatsApp, etc., etc.” That is to say, there isn’t a

single unanimous reading of the perception of the role of the Internet as regards extending the control that older people have over their lives.

The same occurs with healthcare information. Even among the participants who are most familiar with the use of the Internet from groups A and B, there are nuanced assessments about its capacity to give them more independence. Certainly, being able to add to the information given by a physician, ask for a medical appointment, find out more about one's own illness or that of a family member, and verify the ranking of a hospital or of a healthcare professional are thought to constitute clear progress and provide powerful tools to the average person. But they also see the risk they run – particularly as people at an age when health concerns are more frequent – of getting hooked or overly taken up with health issues online.

## **5. Conclusions**

The majority of Internet users in the three focus groups use the Internet to obtain and explore information on health, and have a set of criteria that allow them to avoid sources that they believe to be unreliable. They frequently use the Internet to complement the information given by physicians but this does not replace visits to professional health care providers. Older people still trust their physicians and, in the case of the non-users of the Internet, they have no doubt that it is always better to go to the doctor rather than consult “Dr. Google.”

It may be the case that older people with more access to healthcare information online and facilities to obtain data on habits for healthy living and on the symptoms of diseases are more likely to go to a physician because they can identify a possible health problem sooner. However, they also run the risk, as some of them warned, of becoming “cyberchondriacs,” overly preoccupied with health issues. On the other hand, the older people with lower socio-economic levels from the three groups were those who had the least capacity to access online healthcare information. Those from lower socio-economic groups also run the highest risk of becoming ill.

The researchers saw that the participants who look for information online have appropriate criteria to differentiate its reliability in general terms. But none of them mentioned or seemed to know whether there were official criteria to give some guarantees of the reliability of the information. Nor did anyone mention the possibility

that some healthcare institutions may use their websites to “sell” certain therapies or drugs.

The balance, however, appears to be positive. Online healthcare information is giving older people the chance to take more responsibility for their own health and, when well founded and well used, online health information can act as part of a safety net that complements the work of healthcare professionals. Being able to compare and contrast the information received from one’s physician is in itself an empowering development.

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