

The Dutch Website ‘SeniorGezond’: An illustration of a road map for the informed patient

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Abstract. With the advent of the Internet and its increasing popularity, delivering health prevention is taking on a new form and shape. Internet-based health prevention aims not only to reach more efficiently a wider population but also to sustain an effective communication between patients and the emerging “virtual” healthcare professionals. This paper describes the development and evaluation of a Dutch informative website called SeniorGezond aimed at the elderly population in the domain of fall prevention. The website is a good illustration of how to address the many challenges faced by the Internet consumer of health related information, namely that of accessing good information quality, of searching for relevant information, of comprehending the information retrieved and of acting upon this information. Theoretical models have played a central role in the development process of the website. While the theoretical models should remain transparent to the user, we argue that they act as a support to the road map for patients and citizens. This road map helps to ensure that they can rely on sound information, are given enough breadth of functionalities to efficiently search and are supplied with the appropriate contextualized information that takes into account their existing knowledge of the topics they are searching for.

Keywords: informed patient, health information, health prevention, Internet, road map

1. Introduction

In the past few years, significant changes have occurred in the management of patient care especially with regards to health prevention and disease management. Two main factors have influenced these changes, namely 1) the patient’s changing role and his/her interaction with the health care professionals, and 2) new technological innovations such as the Internet widely used by the general public.

1.1. Growing need for information and patients’ active participation

Patients’ attitude towards their own health and care has evolved. Many patients tend to be more responsible in the management of their health and well-being. Moreover, patients are more involved and take an active role in deciding about and planning their care (e.g. Evans *et al*, 2003). They are turning into active demanders and information seekers. Not only patients but also citizens in general seek to be informed about their health. There is an emergence of a “health self” ideal, driving the endless pursuit of information in order to achieve that ideal (Kivits, 2004). Moreover, there is an increased awareness, amongst the elderly population, that although they may have health problems, they can take action to live healthy. As the aging population is rising and health costs become more expensive, health professionals and policy makers are often stimulating this attitude and the need for more prevention and self-management.

In addition, the Internet has become a popular tool, which offers unlimited possibilities for finding health information. By using the Internet, there is a shift from passive information access to active citizen participation (Okot-Uma, 2000). The access to the Internet also brings a shift in the access to knowledge and with it the access to empowerment (Eysenbach & Jadad, 2001). Indeed, a new health consumer identity is emerging, sometimes referred to as the “on-line self-helpers” (Ferguson, 1997). Via the Internet, patients have the possibility to be better and quicker informed, for example in the domain of health prevention as illustrated with the website SeniorGezond, reported in details in this paper.

People increasingly tend to seek on the Internet tailored and more customized information which can fit their

own personal circumstances (e.g. Cobb & Graham, 2006). Patients with long term illnesses such as diabetes or asthma have specific information needs with regards, for example, to the prevention, management and treatments of their health problems which can change overtime. For instance, SMASHING (developed in our institution) aims to support self management of young patients with asthma (Van Der Meer *et al*, 2006). Another example (also developed at LUMC) is the Cybertraining project which uses Internet technology to deliver a home-based physical activity intervention for patients with Rheumatoid Arthritis (Van Den Berg *et al*, 2006). The application SeniorGezond reported in this paper (see section 2) is focused on health prevention, specifically targeted at the elderly population in the domain of fall incidences.

1.2. *Challenges for the consumer of health related information*

In the search for health related information on the Internet, patients and citizens are faced with several challenges (see Table 1). A first difficulty is that of conducting effective information search on the Internet. The analysis of user logs as we have done in SeniorGezond (see section 3) gives useful empirical evidence on how users tend to search. Furthermore, although the Internet can act as an enabler to support citizens in their health management, one of the problems that citizens face is that of evaluating health information. Over the past few years, there has been an increased awareness of the problems citizens encounter when trying to assess health related websites. As a result, a number of organisations and individuals have devised new ways of helping Internet users find information that meet a defined threshold (such as user guidance tools, accreditation labels and filtering tools). However the access and assessment of good quality information remains for most patients and citizens a very challenging task. Our own analysis (Alpay *et al*, 2007) shows how difficult it can be for a layperson to assess on his/her own the information quality of health related websites. It is clear that there is a gap between the assessment tools that are at the citizens' disposal and their usability in real life. Moreover, information quality is not only about single pieces of information. It is also about how the various pieces of information are organised in a meaningful way for the users.

User's questions
1. Where can I find relevant information?
2. How can I assess the quality of the retrieved information?
3. Is the information relevant for me?
4. Given the information found, which actions do I need to take (if any)?

Table 1: Users' challenges

The next step after finding the required information (and possibly assessing its quality) is that of understanding the information retrieved. This also remains for the user a difficult challenge. Our current investigation on the contextualization of information with the website SeniorGezond (see section 4) opens the door to more insights on how to address this problem.

1.3. *Challenges for the providers of information*

In parallel to the user's challenges, the providers of health related information are also faced with several difficulties. They need to consider, for example, how to present relevant information to the targeted group and how directive the information should be. Developers of informative websites are responsible for ensuring that the website's visitors can easily find their way around the website, and are provided with not only up-to-date information but also with customized information which takes into account their knowledge of the topic they are search for. The next section will report on how we have addressed these problems with the website SeniorGezond.

2. The website SeniorGezond

This section describes various facets of SeniorGezond¹ (Alpay *et al.*, 2004), namely, its information structure, its functionalities and its theoretical basis. The evaluation of the website is described in section 3 while our follow-up investigation with SeniorGezond is presented in section 4. Relevant issues which have emerged from the development process of the website are described in section 5.

2.1. Motivations

Falling is a major health problem within the elderly population. About one third of the elderly fall at least once a year, and due to demographic ageing, the group of elderly will expand (Tromp *et al.*, 1998). Unintentional injury is the sixth leading cause of death in persons older than 65, of which a majority can be attributed to falls. In addition, falling causes a high burden of morbidity and decreases mobility. Several studies have shown that fall prevention is possible (e.g. Perell *et al.*, 2006). The website SeniorGezond is build to inform and educate the elderly and their caregivers about the risks of falling and present them with possible actions that they can take to prevent falls. As such, the SeniorGezond website gives patients and citizens a means to better manage their own health situation and provide them with information to improve their health related habits. By providing the elderly with complete and correct information about the possibilities to prevent falls, it is expected that their awareness, engagement and knowledge will improve.

Many people and organizations have contributed to the development of the website. The department of Clinical Informatics and the department of Gerontology and Geriatrics at Leiden University Medical Centre (LUMC) worked together with the Dutch research institute TNO Quality of Life². In addition, many professionals in the domain of fall incidences worked on the contents of the website (see section 2.3). In order to give information about organizations that are relevant to fall prevention (e.g. organizations that sell aids or offer services to the elderly) we cooperated with Zorgwel Rijnland³ which provides addresses and background information on health, living, and well-being organizations for the region South-Holland North.

2.2. Information structure

The information structure forms the backbone of the various pieces of information necessary to make knowledge accessible to the users. For reasons of readability, the information structure is presented before the theoretical models which support it (see section 2.5). The information structure within the website is structured around problems of fall incidences, and contains four levels of information. The top level Causes of falling includes frequently occurring problems in the domain of fall incidences e.g. dizziness. The second level below Solutions focuses on possible interventions and advices associated with the causes of falling e.g. use of a walking aid. Solutions are supported by the third level Products & Services e.g. walking aids, fitness programmes. From the 'Products & Services' level, users can access the Supportive Facts which makes up the fourth and lowest level of the information trees. Supportive Facts contain addresses about where to purchase products and services, as well as insurance related information. The four levels take the user from general to specific information.

2.3. Contents development

The quality of the contents is an important aspect of an educational website and should not be overlooked (Kim, 1999). In order to develop the information contents of the website, we made use of: 1) two editorial boards; 2) guidelines about fall prevention developed by the Dutch Institute for Healthcare Improvement (CBO, 2004; National Institute of Clinical Excellence, 2004); and 3) literature about interventions for fall prevention (e.g. Gillespie, 2003).

The website contains about 140 web pages that are structured into the levels mentioned in the previous sections. The editorial board responsible for developing the contents was composed of four professionals in the field. Topics to be implemented were first selected and the actual contents was then written up by this editorial board. A larger editorial board comprising of 14 professionals specialised in subfields of fall incidences checked all the contents. In addition, someone from the 'Patient Education' department at LUMC checked the readability of the contents. The information within SeniorGezond focuses on different risk factors at the same time, because of the multifactorial

¹ <http://www.seniorgezond.nl> (SeniorHealth in English). Website is in Dutch.

² http://www.tno.nl/kwaliteit_van_leven

³ <http://www.zorgwelrijnland.nl>

nature of fall incidences.

2.4. Functionalities

The website has been developed through several cycles of prototyping, with the cooperation of the target audience. The website includes several standard functionalities such as a keyword search, a site map, and an index. In addition, the options 'About SeniorGezond' and 'Justification' give background information about the website and its contents. The website also includes functionalities developed solely for this website, such as a health appraisal instrument. By filling in the health appraisal questionnaire, visitors are guided to relevant 'Causes' pages that fit their personal situation. Furthermore, the website incorporates a set of 'Practical Problems' which occur in daily life such as 'Fear of falling while taking a shower' and 'Difficulties with standing up', and the basic navigation via the information trees. These various functionalities present in the website are meant to support users in their information retrieval process and help them to search in an efficient way.

Figure 1 shows a screen dump of the website. A typical SeniorGezond webpage has three panels:

1. The left vertical panel includes the three information trees 'Causes', 'Solutions' 'Products and Services'.
2. The centre vertical panel (in the middle of the screen) gives information about the current page in view. The justification of information is positioned at the bottom of the information page.
3. The top horizontal panel includes other functionalities for searching, for instance, via the 'Practical Problems', the 'Health appraisal tool', the keyword search or using the site map and the index list.

SeniorGezond provides relevant information to different types of users, namely, the elderly (the main group), the family carers and to a lesser extent the healthcare professionals. In recent years, the principle of "design for all" has emerged in order to reduce the gap between able-bodied people and those with special needs in the use of computer technology. In the context of SeniorGezond, we have reviewed existing guidelines on website design for the elderly (NIA, 2001) and for people with handicap (Drempelsweg, 2006). We have also paid attention to general design guidelines (Useit, 2006). Using this approach, we believe the website provides a good level of functional accessibility.

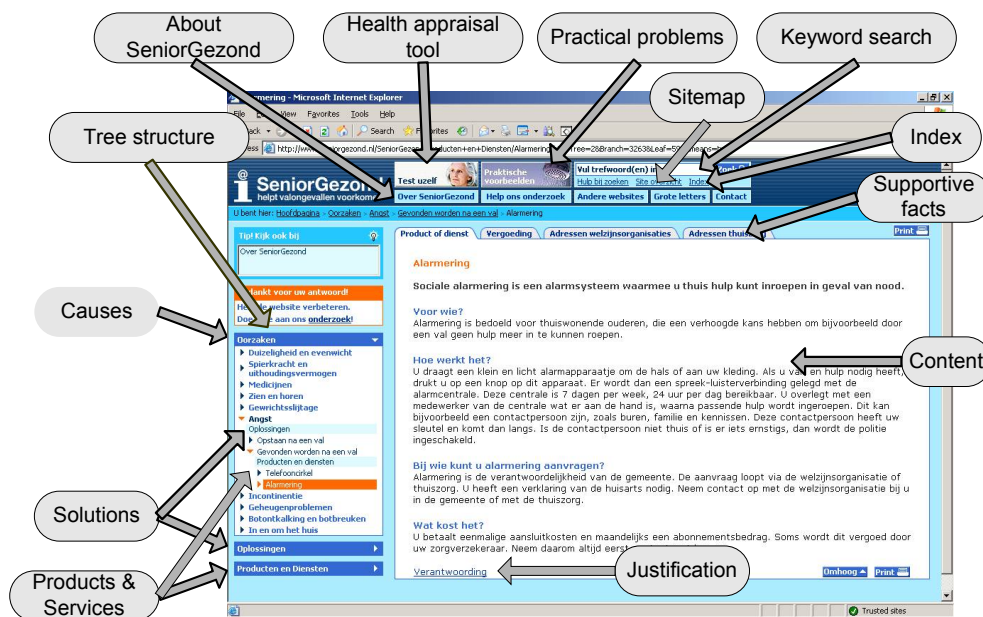


Figure 1: Screenshot with annotations of the different components in SeniorGezond

2.5. Theoretical models

The website has been designed with two theoretical models in mind. One theoretical model has been used to support the structure and the organisation of the information. Another theoretical model has been used to support information retrieval and thus providing users with a basis for efficient information searches.

2.5.1. Information structure based on the Precaution Adoption Process Model

Given the many different aspects of fall prevention, the website contains a large amount of information. A good information structure can facilitate easy access to relevant topics within the website and help to make a distinction between general and more specific information. Behavioural and social science theories are useful in planning interventions for health prevention. These theories provide insight into how interventions can be shaped to reach people and influence them (Trifiletti *et al*, 2005). In order to organize the large amount of information and to focus on users with different information needs, the contents was structured using the Precaution Adoption Process Model, a health behavioural change stage theory (Glanz *et al*, 2002; Weinstein *et al*, 1998). Users need information that fit the stage they are in, and that helps them to move to the next stage of the model where eventually, they might take and maintain action to prevent from falling (Armitage & Conner, 2000). The stages of the model were translated into a users' information need and thereupon converted into the information levels of SeniorGezond (Figure 2). By developing an information structure based on a health behavioural change program, a tailoring is offered to the visitors. They can make choices by selecting certain branches in the structure, where relevant information which matches their readiness for change is provided.

<u>PAP Model</u>	<u>User's need</u>	<u>SeniorGezond</u>
1 Unaware	Awareness of hazard	'Causes' of falling (general)
2 Unengaged	Think of oneself as belonging to a risk group	'Causes' of falling related to personal situation
3 Deciding about acting	Weight pro's and con's of interventions	'Causes' of falling (general)
4 Decided not to act	4 N/A	4 N/A
5 Decided to act	5 Develop implementation plans	5 Solutions
6 Acting	Need to know what one can do	Products & Services
7 Maintenance	Keep motivation	N/A

Figure 2: Precaution Adoption Process (PAP) Model in relation to the information need and information levels within SeniorGezond (N/A means 'not applicable')

2.5.2. Information search based on the Cognitive Model of Information Search and Retrieval

The user of the website needs to be able to search and retrieve relevant information in an effective and efficient way. In order to support the user's problem solving skills for information retrieval (IR), we have used as a theoretical basis the cognitive model of information retrieval proposed by Sutcliffe and Ennis (1998). This theory is interesting because it is a synthesis theory of IR that builds on previous models of IR process and incorporates experimental evidence of user information seeking behaviour.

The cycle of information seeking comprises four main activities: 'Problem Identification' where, the user's initial goal and information need are formulated by him/herself, 'Articulating Needs' where the user's information need is expressed as concepts of the domain knowledge, 'Query Formulation' where the conceptual needs are transformed into keywords and query syntax employed by the system, and 'Evaluating Results' where the user can assess the retrieved results against his/her information need. In this information retrieval cycle, problem identification is the entry point. Searching then proceeds around the cycle with articulating needs, and query formulation. Evaluation of results may lead to reformulating a query. All the phases, except 'Problem Identification' have been implemented into the website⁴.

⁴ We took the view that this phase largely remains in the user's head and thus it was not implemented. The user's information needs will 'comes out' during the Query Formulation phase. Helping the user find out about the website contents is a way to guide him/her in identifying his/her information need.

'Articulating Needs' is implemented within the website in three ways: i) through the support of the information trees. ii) through the use of an index which lists the main keyword terms from the website, and iii) through the health risk appraisal questionnaire. 'Query Formulation' is implemented using various search options such as the keyword search, the information trees, the index, the site map and the list of 'Practical problems'. During the phase 'Evaluating Results', results of the search are coupled with an estimate (in percent) of how closed the result is from the word being sought. For example, when searching for 'walking aids' the user will get 100% for the page where 'walking aids' is the main topic and 37% when it is only mentioned in relation to medication.

The evaluation of results also relates to being able to assess the quality of information provided. Although a number of criteria have been identified, the usability of the criteria is still a problem for the users (Eysenbach and Köhler 2002). In the context of SeniorGezond, a number of criteria have been considered. For example, the accuracy criterion is implemented by having for each page the information sources specified. The last date of control deals with the information currency. The authority of the website is identified by the display in the home page of the logos of the developers LUMC and TNO (known to the Dutch public), as well as by the information given in "About SeniorGezond". The objectivity of the website is clearly stated in the home page. Finally, the coverage of information is valued 1) through the various examples given throughout the website and 2) by the large number of topics which were chosen from the editorial board.

3. Evaluation of the website SeniorGezond

3.1. Methodology

An evaluation was conducted to find out how the information structure was used. Web logs from the website's visitors were collected during an eight month period⁵ (from September 2004 until April 2005) and subsequently analysed. During this period 35535 visitor accessed SeniorGezond with an average of 1,7 hits per visit. Among others, the logs contain the web pages requested and the date and time when these requests were issued. To gain a better insight into the behaviour of the website's visitors, we clustered the requests into visits. A visit is a sequence of requests issued by the same visitor within a limited time interval. We did not make use of cookies because of privacy concerns. Therefore, returning visitors were counted as different visitors. Logs from search engine robots and from activities from the developers were removed. In order to clarify the navigation pattern within the information structure, movements between levels were manually encoded. Only visits lasting at least five minutes and containing more than five hits were considered (in total of 832 logs). To obtain a representative sample, we took 250 random numbers from these logs using the sampling with replacement method. With this approach 214 log files were identified and finally analyzed.

3.2. Results

The 'Causes', 'Solutions' and 'Products & Services' levels were extensively used by SeniorGezond visitors. The 'Products & Services' level was accessed (34,2%) as much as the 'Causes' level and the 'Solutions' level combined (15% and 15,6% respectively). The 'Supportive facts' level was accessed by a smaller number of visitors (4,1%). It should be pointed that each level of the information structure contains a different number of pages. The 'Causes' level has the fewest pages (11), followed by the 'Supportive facts' (17), the 'Solutions' (27) and the 'Products & Services' (82). Figure 3 shows that the average number of visitors per page declines in the subsequent levels of the information structure.

⁵ The evaluation took place at the time that the website went officially online.

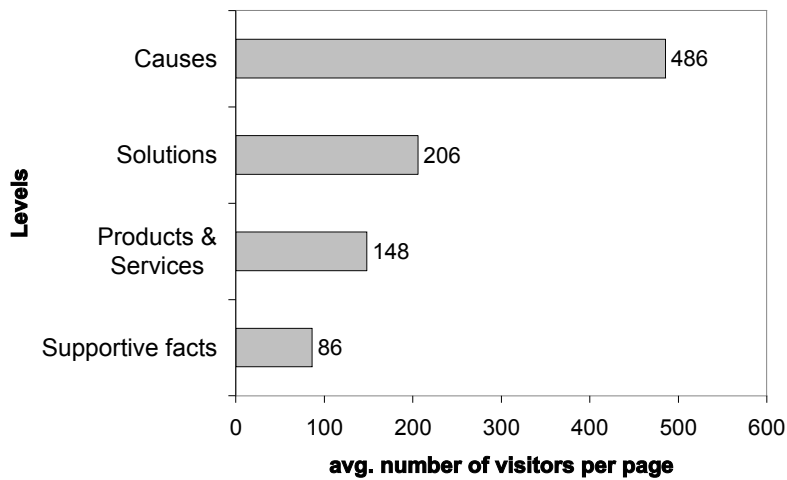


Figure 3: Average number of visitors per page per level of the information structure (n=35535)

The number of transitions between the levels of the information structure of the 214 exploratory visits is shown in Figure 4. Most transitions occur at the same level, i.e. ‘Causes’ to ‘Causes’, for instance, from *Dizziness and balance* to *Muscle strength and fitness*; ‘Solutions’ to ‘Solutions’, for instance, from *Proper use of medicine* to *Physical activity* and ‘Products & Services’ to ‘Products & Services’, for instance, from *Automatic lighting* to *Drugs telephone information service*. The number of transitions between pages of the ‘Products & Services’ level is probably much higher since there are many more pages at this level. In addition, transitions between ‘Causes’ and ‘Solutions’ and between ‘Solutions’ and ‘Products & Services’ were made frequently. The transition from general (i.e. causes) to more specific (i.e. products & services) information occurs more frequently than this other way around.

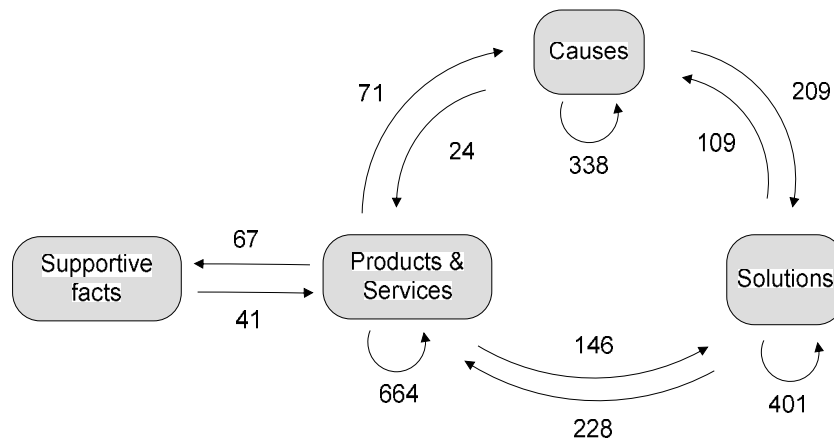


Figure 4: Visualization of the navigation patterns of the exploratory visitors of SeniorGezond. The number of transitions between the different levels in the information structure are illustrated (n=214). The total number of transitions is 2298.

The most popular pages were about making the home and surroundings safer and more comfortable (29,8% of total hits). Results of the evaluation also showed that the online health appraisal instrument changed the distribution of the topic selection. In particular, the access to the topics *Fear of falling* and *Osteoporosis* was increased (6 % for general visitors vs. 52% for tool users; and 8% vs. 49% respectively). This tends to show that the guidance to relevant information can be enhanced by using a health appraisal instrument, which leads visitors to information that is applicable to their personal situation.

Of the entire search and browsing facilities, the keyword search was the most commonly used. However, about 70% of the visitors of the information structure of SeniorGezond accessed the contents directly from outside

SeniorGezond, for instance from search engines or from the computer's cache, thus bypassing the website's homepage.

4. A step further with SeniorGezond: Towards a contextualization of information

The current online version of SeniorGezond addresses the problems of the structuring and of the quality control of the information as well as that of supporting efficient information searches. However, the problem of the user's understanding of the information has barely been tackled. Understanding information is closely related to that of the contextualization of information (i.e. supportive information) which can not only help improving the user's understanding and but also sustain an effective communication with the 'virtual' healthcare professionals. In the SeniorGezond website, the information trees provide a structure that goes from general to specific information. The level 'Solutions' holds a central position between the 'Causes' level and the 'Products and Services' level and embeds some initial elements of contextualization. The level 'Solutions' and the links between the four different levels are considered of intrinsic value to the contextualization of information.

4.1. Theoretical Model of Communication

In order to investigate the impact of contextualised information on the user's understanding of the retrieved information and thus on his/her communication with the 'virtual' professionals, we have been guided by the model of communication proposed by Te'eni (2001). Central to the model is the idea of context. Contextualization is about providing supportive information to explain a core message and is seen as a communication activity aimed at increasing a mutual understanding amongst the communicators.

Contextualization is about providing information, which is explanatory and supportive to convey the health message, and to enhance the user's understanding of the message. The contextual information will increase the likelihood that the user (as receiver of information) will understand the message he/she has received via the Internet. Within the boundaries of a health website, contextualization might be more constrained than when searching using a general search engine, but not necessarily present as needed. As Te'eni stresses contextualization is necessary when a message is liable to be misunderstood. This is especially true when dealing with health related information, which may impact on someone's well-being.

4.2. Empirical investigation

In practice, visitors of health related websites will have different levels of knowledge and understanding about the healthcare topic they are searching for. We have started to assess empirically the impact of contextualization (or lack of it) on mutual understanding. That is, we are testing whether the user's cognitive distance (i.e. the difference in knowledge between the user and the website) will affect the complexity of the communication (Alpay *et al*, 2006). Based upon the Te'eni model, a user with a low cognitive distance (i.e. a person knowledgeable in the field) will have a high level of mutual understanding whether or not they use contextualization. Conversely, a user with a high cognitive distance (e.g. a non-knowledgeable person) is expected to have a low mutual understanding with no contextualization (e.g. a missing level of information, a missing link between the levels of information) and a high mutual understanding with contextualization.

A feasibility study with eight participants was conducted during the spring of 2006. In this study, participants were assigned to groups (knowledgeable vs. non-knowledgeable) depending on their prior knowledge of the domain. Within both groups, participants were given exposure or no exposure to contextualization, which resulted in four experimental groups. As outcome parameter, we used the participants' understanding of the domain after visiting the website. With such a small number of participants, it has been difficult to obtain any significant result. However, the pilot study has helped to review and improve the study design and check on the methodology used for coding and analysing data. Collecting data for the main study has already started and is, at the time of writing this paper, still in progress.

5. Discussion

The website SeniorGezond provides a good illustration of how to address the many challenges faced by the Internet consumer of health related information., namely that of accessing a good quality of information, of searching for

relevant information, of comprehending the information retrieved and of taking action (if necessary). The development of the website SeniorGezond and the follow-up investigation has brought us to frame three relevant components in the development of health related websites, corresponding to the above challenges (see Figure 5). We considered these as crucial if one is to support patients and citizens in their quest to become informed and actively involved in their own care. Theoretical models play a central role in the development process of the website. While the theoretical models should remain transparent to the user, we argue that they act as a support to the road map for the information consumer. This road map helps to ensure that the information consumer can rely on a good quality of information, is given enough breadth of functionalities to search efficiently and is supplied with the appropriate contextualized information.

Within SeniorGezond, two theoretical models have been implemented, the PAP model for health prevention, and the cognitive model for information retrieval. The theoretical model of communication has not been implemented but rather serves as a guide in our investigation of the contextualization of information.

The three pillars of this road map are of relevance to patients and citizens who want to become better informed and active in their own care. Becoming informed involves skills and competencies. The components "Information Quality" and "Information Search" have a direct impact on someone's information literacy as well as on their health literacy (Kerka, 2003). These skills are needed when searching within health related websites. A lack of information literacy skills coupled with little health literacy can inhibit the emergence of the informed patient identity (Henwood *et al*, 2003).

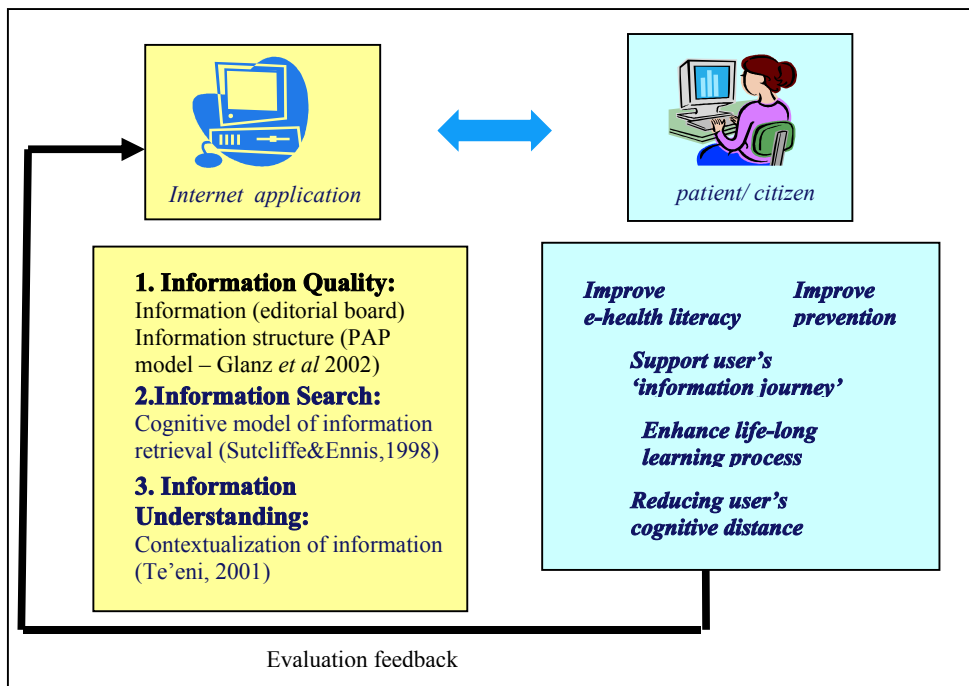


Figure 5 : The roadmap for the informed patients/citizens

Information seeking does not occur in a vacuum but rather underpins the person's motivations and focus, and what has been referred to as the "information journey" (Attfield *et al*, 2006). The information journey has three stages: 1) information initiation where information requirements are initiated, 2) information facilitation for the retrieval of the required information and 3) information interpretation in order to support information interpretation and/or modification. While Attfield *et al* studied the information journey in a broad scope, we focus on the information journey within an electronic health resource such as a health website. The contextualization of information can be seen as an accompanier and a "tuner" to a person's information journey. In SeniorGezond for instance, the contextualization of information through the information structure can be viewed as supporting the user's information journey from general (the causes of falling) to specific information (products to purchase). Gathering good quality and contextualized information can ensure that informed patients be fully equipped to pursue his/her information journey.

Becoming an informed and self responsible patient is a lifelong learning process (Jones *et al*, 2000). This is

especially true for patients with long-term illness such as diabetic patients. We foresee that the contextualization of information has a role to play in enhancing the website visitor's health literacy and eventually his/her lifelong learning development. A better comprehension of the terminology employed through contextualization can reduce the cognitive distance between user and website and sustains an effective communication. In SeniorGezond for instance, attention has been given to provide a clear definition and explanation to the terms used in the domain of fall incidences.

Building a profile of the consumer of health information is not an easy task. The improvement of someone's health literacy or the impact of an informative website on someone's life long learning process need to be measured through empirical work. Results from these measurements need to subsequently be feed backed into the development and improvement of the Internet application.

6. Conclusions

The delivery of health prevention via the Internet has become a reality. The development of a website such as SeniorGezond has helped us to uncover the many facets of Internet-based health prevention. Much can be learned from its development process. The Internet as the communication medium can hamper communication between patients/citizens and healthcare professionals, as well as the delivery of health prevention. Our experience with developing SeniorGezond provides a step towards addressing this problem.

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