

European digital content for the global networks

# EDC-22071 KOM2002/27938 Groupware for Distributed Content Production KOM2002

# An Evaluation of Web4Health –

# Patients and Racket-hall Visitors' Use of a Website on Mental Health

Security (distribution level)	Public
Contractual date of delivery	August 2004
Actual date of delivery	January 2004
Deliverable number	D 7.3A
Deliverable name	Final Evaluation Report: Attachment A, An Evaluation of Web4Health –
	Patients and Racket-hall Visitors' Use of a Website on Mental Health
Туре	R
Status & version	Final report
Number of pages	10
WP contributing to the deliverable	WP7
WP / Task responsible	University of Ioannina
Other contributors	KTH, FP
Author(s)	Minna Forsell
EC Project Officer	Kimmo Rossi
Keywords	Content; mental health; evluation; usage, user studies
Abstract (for dissemination)	The purpose of this explorative study was to find out how Swedish users responded to Web4Health, a web-site about mental health, funded by the European Union. Twelve group-therapy patients and ten racket-hall visitors have tried the site by asking it a question about a psychological problem; thereafter, they have been interviewed. Subjects found the use of the web-site a valuable experience, and the interest in it was high. More than anything, the site stimulated the subjects' thinking about their own situation. This was not only caused by the useful information that they got; equally important was the information that they rejected. We have borrowed a term from computer game developers, and called this "the cocktail party host effect": i. e. the provocation caused by information that did not fit the user's needs gave rise to new thoughts and stimulated the subject to get more engaged in his or her problem.

An Evaluation of Web4Health –	
Patients and Racket-hall Visitors' Use of a Website on Mental Heal	th

Minna Forsell Supervisor: Jacob Palme Nov-dec 2003 The purpose of this explorative study was to find out how Swedish users responded to Web4Health, a web-site about mental health, funded by the European Union. Twelve group-therapy patients and ten racket-hall visitors have tried the site by asking it a question about a psychological problem; thereafter, they have been interviewed. Subjects found the use of the web-site a valuable experience, and the interest in it was high. More than anything, the site stimulated the subjects' thinking about their own situation. This was not only caused by the useful information that they got; equally important was the information that they rejected. We have borrowed a term from computer game developers, and called this "the cocktail party host effect": i. e. the provocation caused by information that did not fit the user's needs gave rise to new thoughts and stimulated the subject to get more engaged in his or her problem.

#### Introduction

In helping people to improve their health, communication of health information is an essential part. Nowadays, *health* is a much more complex notion than ever – it does not simply imply absence of sickness, but includes both mental and physical aspects, and the subjective sense of well-being. Health is no longer just the opposite of sickness, but an over-all term which is hard to measure – ultimately it is about how the subject perceives and experiences his or her own life, and how he or she handles the situation he or she is in (Alfredsson, 2).

A consequence of this is that the strategies people look for to achieve a higher state of health become increasingly personal and singular. Thus, health is now a *personal* construction rather than an objective *fact* – whether or not a person "feels" good about her life is a decisive factor in judging someone's health.

Even though people in the Western World are getting physically healthier and live longer lives than even, more and more people *feel* worse, and worry more about their health. Concurrently with this, counselling has become increasingly popular. In getting help, an increasing amount of people are not comfortable with general guidelines for healthy living, but demand personally designed help. Now, how can these people be reached?

Personal advice-giving is an ancient method of helping people with problems. *Personal* does not mean that it is *private*, however – a lot of the advice that has been given throughout times has been delivered publicly, so that more people than those involved have been able to learn from the examples.

A popular form of public advice giving is the *advice column*. Traditionally, it answers the readers' questions with a mix of information, advice, and moral attitudes. In the beginning, the column's advisor referred the readers to expert opinion; today, the advisor *is* the expert. In order to reach the public, however, an advice giver must be more than an expert. More than anything, a public advice-giver must be a *performer* (Paul, 56). In order to influence the lives of people, the advice-giver must be able to attract people's *attention*.

Nowadays public advice giving is administered on today's streets and squares: in magazines, on TV, and on the Internet. On Google, the amount of searches on the term 'depression' widely exceeds the searches on e.g. 'heart disease'. Through faceless communication, the Internet offers people the possibility to get information without revealing their own identity. This anonymity makes it possible for the client to be more honest in intimate matters; when confronted with a person, e.g. one's doctor, patients often leave out important information about their feelings about getting a diagnosis, about alternative treatments that they are trying out, and about not wanting medication (Shuyler, 3). As a consequence, the doctor's prescription might not be for the person the doctor has in front of him, but rather for an illusory patient.

Behavioural scientists at Stanford have found that Internet-users look for the same qualities in the contact with a web-site as with a human being. A bureaucratic web-site angers

us and makes us feel that no one is listening. A successful site, however, is vital; it breathes and has a clear voice – just like when someone is there for you, ready to help (Isbister).

Web4Health is a project, financed by the European Union, which aims to develop a website for communication of high-quality information about problems related to mental health. Experts in five European countries co-operate in order to briefly, intelligibly and comprehensively answer questions from web-site users. The system could be characterised as a *serious and extended advice column*: private problems placed on public view, just as in the traditional advice column, but with *numerous* experts giving *direct* advice, instead of one advisor referring to experts. Users can choose a topic, or ask direct questions.

Up to now, Web4Health has only been available in English, but is being translated into different languages. The purpose of this explorative research paper is to investigate the needs of Swedish users by inquiring into two things: 1) How do our research subjects use and respond to Web4Health? 2) In what ways can the web-site help subjects improve their health? From this, we hoped to develop some ideas about how to best adapt the content of the English web-site into Swedish.

#### Method

# Subjects:

Two groups of subjects were included in this study. The first consisted of 12 group-therapy patients, three men and nine women of ages 19-60 years. These subjects all received group psychotherapy at the time of the study. We wanted these people to try the web-site because they were familiar with psychotherapeutic treatment and because they had identified themselves as help-seeking.

The other group consisted of ten people, four men and six women of ages 17-45 years, who worked or trained in a racket-hall in the outskirts of Stockholm. We expected these to be people who saw themselves as healthy and mentally stable persons, and who had not been in much contact with the psychotherapeutic culture. One person in this group had, however, gone through psychotherapeutic treatment for two years.

#### Material:

The subjects used a computer with the Web4Health web-site. The subjects of group 1 filled out a questionnaire afterwards, and all subjects were interviewed. The questionnaire as well as the interviews focused on three variables: the user-friendliness of the web-site, the quality of the information, and the usefulness of it to the subjects.

# *Procedure*:

Subjects were informed that the purpose of the study was to evaluate a web-site containing information about mental health, financed by the European Union. They were also told that any information about themselves was strictly confidential, and they were encouraged to freely speak their minds. Subjects then got to try the web-site after getting the following instructions:

"Here you have a web-site about mental health. On this web-site you can pose questions about psychological problems and receive help. I would now want you to think about a psychological problem that you want to know more about; then I would like you to try the web-site to find an answer to your question. You can start whenever you are ready."

Subjects were observed, and after having received an answer or after ten minutes, the subject of group 1 got to fill out the questionnaire. One week later they were interviewed. Subjects of group 2 did not fill out the questionnaire, but were instead interviewed right away.

#### Results

In general, subjects wanted *expert knowledge presented in an entertaining style*. As to how the subjects related to the site, mainly three metaphors were used. The most common one was to understand the web-site as some kind of *magazine*. One female patient called the answers she read *articles*, and described how she read the first lines as an introduction, which would decide whether she would read the rest or not. 'Interesting' meant, to this woman, that there was something in the text that she was *personally familiar* with, and that she could identify with. Another subject, a female racket-hall visitor, resembled the site to an esoteric medical magazine. This person found the site too serious, and not *entertaining* enough. "It's a bit boring... but I suppose we're not out to have fun here, are we?" Throughout, subjects were annoyed with difficult texts. many of these subjects also wished for more colour, more pictures and a more vibrant site-design. "More like a tabloid." as one subject among the patients put it.

Among the racket-hall visitors, another conception of the web-site was more common; many likened it to an *encyclopedia*. Some saw it as a mini-Google search-site on mental health. "This kind of site is very good if you want to ask about something that is unclear to you. I mean, it is very expensive to go to the doctor's just to *ask* about something." said a female subject in the racket-hall. This was a commonly held view among the racket-hall subjects, and one subject, a young man, also pointed out the anonymity factor: "here I could ask about the things that are taboo elsewhere." Although in this study the anonymity factor was not at work since the subjects were being observed, these subjects nevertheless saw the site as a resource in finding information about such matters that are taboo in their everyday life.

A third understanding of the site was to see it as a *friend*. This was most common among the patients, who were probably influenced by the fact that their therapist is involved with the site. Thus they were prone to start *telling* the site certain things, correcting it and explaining their situation. This was not common among racket-hall subjects, who showed a less emotional response to the web-site.

#### Interest:

Throughout, the interest among the subjects was big. Independently of computer-experience and language-abilities, all subjects showed interest in the web-site, and not one of them was indifferent to the task at hand. Information about mental health was considered an engaging and relevant subject.

All of the patient wanted to visit the web-site again, irrespective of what kind of answers they had got. Eight subjects out of twelve estimated the web-site as "good" or "very good".

In the racket-hall, subjects were equally interested, but somewhat more sceptical. Two subjects were doubtful about whether they might visit the web-site again, but both of them mentioned a scenario in which it might come into question. "Perhaps if there was something *pressing*... something you didn't know so much about. Something you couldn't ask other people about." To the subjects in the racket-hall, a visit on a web-site like Web4Health was associated with something that you might do if you had nowhere else to turn.

#### *Subjects'* use of the web-site:

Independently of computer-experience, most subjects found the site easy to use. Several of them commented upon how fun and practical it is to be able to "jump around" between the answers – to be in control of where they were going. They also appreciated being able to easily find related answers with a particular button; it spurred them to continue. When pages without any links came up, however, they were considered "dead", and the subject gave up.

Being able to continue in different directions clearly enriched the search. An answer always awoke many new thoughts, questions and ideas, and the subjects appreciated being able to choose which one to follow up. "This answer makes me feel that there are further *keys* for me to find here, as it were..." as a female subject in the racket-hall put it.

The commonest method of use was the "jig-saw puzzle method". Among the patients, most subjects treated the content of the site as "pieces of a jig-saw puzzle", and they described how they construct the picture (and solution) of their problem by reading some here, some there. The pieces of information form a whole, which reflects the problem that the subject is having.

# What did the subjects look for?

Throughout, subjects looked for *information, personal advice and empathy*. But there were deviations: one subject, a female patient, expressed her deep tiredness of actually *getting* answers to her questions. She no longer wanted wise advice, because she had already got it all, and it had not helped. This woman had suffered from a chronical disease since childhood, and had tried every thinkable treatment for it, without getting better. She was no longer responsive to further suggestions, but what she wished for was *relief*. "What if someone else got to have my disease for a while, and live with it. *That* would be something. *That* would be *really* nice..." she said apropos what kind of help she would like from a web-site of this kind.

Some patients wanted a plan of action, but mostly they looked for general advice. Some wanted understanding of their symptoms, or insight about how their symptoms were related. A middle-aged male patient put it like this:

"You seek knowledge to get new understanding. You seek the ultimate answer."

"What would that be?"

"The ultimate answer makes you understand. It gives you the little piece of the jig-saw puzzle which makes you see the whole picture. It is the answer that makes you not have to come here (to the therapist's) no more."

This statement shows the common wish among patients to get that little piece of information that you have hitherto missed in your personal jig-saw puzzle. Another common wish among those who asked about their own problems was to have that problem viewed from different perspectives. They wanted an *overall view* of a particular problem, what might have provoked it, how it could be treated and what it might lead to.

Those subjects who used the web-site information to understand their surroundings better, wanted, above all, high-quality information from certified experts. These subjects were also particular about the objectivity and professionalism of the answer: one subject was deeply annoyed by an answer in which the expert *diagnosed* the one who had sent the letter. "What can he possibly know about that person's situation?" the subject commented. "You can't diagnose people when you only have a few lines to go on."

Incidentally, it could be mentioned that several of the patients also showed a need to *tell their stories*. These subjects did not always want more answers or information, they just wanted to tell what worried them. Sometimes they tried to write their story in the natural-language panel.

All patients posed questions related to their own lives and problems. Most of all, they wanted help directly for themselves, they wanted answers that would relieve their mental pain right away. They wanted something new and powerful – like quick medicine. The racket-hall visitors, on the other hand, asked about outer phenomena, e.g. about problems for people around them, or information for a school-project. The racket-hall visitors were first and foremost interested in getting *information*, and perhaps a fresh view on things in general. They rarely sought advice, and in general they did not find the answers applicable to their

own, personal lives. Rather, they wanted to extend their knowledge and perhaps become aware of something new.

Many subjects, mainly patients, looked for confirmation of what they already knew. "That was *definitely* the best thing about it – that you got confirmation of what you already knew. The site works as a short-cut to confirmation", one male patient said. Thus, in general, the patients wanted to have their knowledge confirmed, to find out something new, and to get information that would be applicable to their personal lives.

# *The quality of the answers:*

The quality of the information that the subjects got was consistently estimated as good. Only four of the subjects found the answer they read less good than OK.

The quality of the answer was dependent not on content, but mainly on the *way* it was written. It should *sound* professional, something that is essential on the Internet, where "crappages" are abounding. Although racket-hall visitors in general found the tone of voice professional and trustworthy, it was considered much too medical by some. This might be due to the particular answers these subjects got: the tone of voice in different Web4Health answers vary a lot according to who the writer is. The subjects who sought answers to their own problems wanted, more than those who just wanted information in general, *popular language, comprehensible analysis and empathy*. This is not surprising, since these subjects reached out for a friend, as it were, not only for a source of information.

The language in which the information was communicated was decisive to whether subjects would use a web-site like Web4Health. "It (English) is not my language. Even though you master a foreign language it can never reveal the same amount of nuances to you as you can perceive in your own." a female patient said.

There was some confusion as to who was behind the web-site. The web-site contains a drawing of a female doctor as an illustration to the term 'medical expert'. None of the patients reacted to this, but almost all of the racket-hall visitors commented upon it. They wanted to know more about the experts, to be able to create an opinion of their own. Many found that professionalism and the intimate information that the site communicates do not go well together with cartoons. Instead, they preferred photographs and text to explain who was behind the information in question.

Obviously, the patients were influenced by the fact that their therapist is involved with the web-site project. Their treatment is aimed at teaching them how to handle problems with constructive common sense, like many of the answers on the site. Thus, the whole web-site idea appealed to the patients, who just left out of consideration those answers that revealed thoughts or theories that they did not recognise.

Two female racket-hall visitors thought that the experts on a Swedish site should be Swedish, whereas two male subjects in the racket-hall found it positive that the site had an American image. Especially those interested in medicine wanted Swedish up-to-date information. "These are not Swedish brands..." one woman exclaimed when she saw a list of medication. "Evidently, it would be essential to supply a relevant list of medication, if it is to be of any interest to the me."

## What impact did the information have on the subjects?

How did the information on Web4Health influence the subject? This is interesting. All subjects said that human contact is absolutely necessary for getting help with personal problems. "A personal problem demands eye-contact" a young man in the racket-hall said. Furthermore, many subjects opposed *information* to *help*. "Sure, I can get information, but help — no." is how one female subject in the racket-hall commented upon the prospect of getting help for herself on the web-site. This was a commonly held attitude towards help on

the Internet in general. Internet could not offer the kind of warmth that only another person can give, and which is essential to get for someone with a problem.

Now, is this true? The Internet is far from being such a hopeless medium for personal contact as suggested by subjects; many people could give witness to how they have established deep relationships on the Internet. Contact through a medium such as the Internet just differs greatly from personal contact face to face. Subjects, however, seemed to be of the opinion that the web-site aspires to achieve something as similar to personal contact as possible. Accordingly, the information received did not have a direct influence on the subjects. They did not change their minds according to the answers that were given, but impact was much subtler than this. Whereas not a single subject had direct use of the particular answer he or she received during the session with the web-site, all of the subjects got something else out of the experience. The great majority got new ideas to investigate. This was clearly the most common effect. Subjects got interested in their problem again, they got engaged and inspired to think anew, perhaps see the problem in a different light. Not in the lighting proposed in the answer, but the suggestions from the web-site opened up the possibility of thinking differently than before. Thus, at best, the process of asking the web-site inspired a restructuring of the subject's personal health-jig-saw puzzle.

#### Discussion

Now, what is there to learn from this study? There is something to learn about user-method, and there is something to learn about how to present information on a web-site such as Web4Health.

As discussed in the introduction, 'health' is a personal construction rather than a fact. Thus, users have their own conception of their problem, and consequently need a matching solution. Who could ever give this, other than the person herself? To the subjects of this study, there is not *one* right solution to a problem; rather, suggestions are *valid* to the *degree* that they are *accepted* by the subject. If the subject does not find the information he or she is given *acceptable*, he or she can just reject it as nonsense. This tells us something about advice-giving on the Internet: if the identity of the advisor is *unknown*, people do not relate to the information the same way they would to a real person. Instead, they value the information according to how well it fits into their personal understanding of their own state of health. Ultimately, it is the receiver of the information who decides how valuable it is.

The subjects of this study expected the Internet advisor to aim at achieving personal contact with the user; however, as we discussed in the introduction, this is not the purpose of a web-site such as Web4Health. The limitations of its form restricts its range of impact; it does not aim to directly reach the private sphere of a certain individual. Instead, just as the traditional advice column, it strives to create an *illusory intimacy*. That is, the user is supposed to feel that there is an intimate approach, but an intimacy that does not include oneself: it is strictly between the advisor and *somebody else*. The question is not from me, but it *could* be a question asked by me. When the user is allowed to switch between these states of mind, a constructive interplay between former knowledge and new information takes place. Thus, a web-site such as this can influence its users by *showing examples* for users to draw conclusions from. The answer is not supposed to be implemented directly, it is supposed to give new ideas and to raise new questions.

Now, did this happen in this study? The question must be answered in the affirmative. All of the subject claimed to get new ideas that provoked their thinking concerning their lifesituation. However, I am certain that this effect could become more powerful. In achieving this, one could seek inspiration from computer-game developers. The success of a computer-game avatar depends on how much the game-player wants to mentally "step into" the identity of the avatar. In the perfect case a Web4Health-text would describe a person who resembles the user enough for him to identify with it, but differs enough to not feel *exactly* as me.

What about the presentation of information? The ideal design of answers is *scientifically sound information presented as articles with a personal tone of voice*. Unquestionably, professionalism, scientific proof and extensive experience are the most prominent Internetadviser virtues. Furthermore, the style of writing should be easily comprehensible, concise and arouse interest in the reader. If we see the web-site as a serious advice column and keep in mind the most common user method, i.e. constructing a jig-zaw puzzle of information, a good idea would be to present the answers as mini-articles that you could collect. Keeping in line with the thought of combining pieces of information into an individually designed whole, short introductions to the main headings would be practical, such as "depression", anxiety", "eating disorders", etc. In time, an extension of the problem areas represented on the web-site will be necessary. Especially "healthy psychology"; as it is now, most questions and answers are concerned with psychopathology. A greater variety of problem areas and subtler grades of pathology would enhance the possibilities for the user to find a suitable and realistic answer to his or her question.

From the user's point of view, the web-site's professional image is impaired by the lack of information about the experts. 'Expert' is a term that needs to be certified, and especially in a medium such as the Internet. The more personal the information gets, the more critical the user becomes.

One problem, as we saw it *before* the study, was the habit of the system to give the user a list of unsorted material. A user searching on 'tiredness' might get a list of answers related to 'anxiety disorder', 'depression' and other serious illnesses. This effect might make users worried, upset or misinformed. However, from the user's point of view the unsorted lists were in fact one of the web-sites merits. How come?

When the list did not answer the subject's expectations, it aroused emotions in him or her. This reaction caused the subject to think, and take a stand. It made the subject more active than those subjects who got expected answers. Now, why is this? We can explain this with the help of a computer system developed by researchers at Stanford. They developed a computer agent called "the cocktail party host" to enable communication between people speaking different languages – this was an agent who intervened in computerised conversations between Americans and Japanese when a so called "awkward pause" arose. In order to get the conversation going, the cocktail party host posed a "awkward question", and then disappeared. This had the effect that the conversation got more interesting than it had been before the intervention. Thus, provocative interventions can enhance the quality of a conversation (Isbister). The same principle seems to hold for computerised advice columns, such as Web4Health. The subject's inner dialogue concerning the problem he or she had, seems to have been stimulated by the provocative lists that sometimes appeared. Instead of being a nuisance, the list had the same effect as the cocktail party host had in the communication-system; it stimulated the subject and his or her thoughts about the problem at hand. When subjects afterwards reflected on the use of the web-site, besides having got information, they valued the unsorted list-effect as the most rewarding aspect of the system.

# **References**

Scientific reports:

Alfredsson, J. "Livskvalitetsmätningar, något för folkhälsoarbetet? – en inledande diskussion baserad på en litteraturgenomgång." 2002. Samhällsmedicin Gävleborg. 2002:2. Landstinget Gävleborg.

Shuyler, KS, Knight KM. "What are Patients Seeking when They Turn to the Internet? Qualitative Content Analysis of Questions Asked by Visitors to an Orthopaedics Web Site." Journal of Medical Internet Research 2003;5(4):e24

# Magazine:

Paul, Pamela. "Dear Reader, Get a Life: Today's Talk Show Therapists and Edgy Advice Columnists are Bolder, and Possibly More Effective than the Genteel Advisers of Newspapers Past." Psychology Today. Vol. 36. Issue 4. Publication date: July-August 2003. Page 56+.

## Lecture:

Isbister, Katherine, Ph.D. "Designing Computer Interface Agents that Support Social Interaction". Stanford University. 201103. DSV, Forum i Kista, Sal 10.