

Social media for the ehealth context. A requirement assessment.

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ABSTRACT

There were 940 million social network users in 2010 in the world (Bellegem Van 2011). This fact makes social network sites (SNS) an integral part of the Internet. Knowing that health affairs are a central topic in the Internet makes this issue into an addressee for SNS. So-called health social network sites promise to be beneficial by lining up with the success of SNS like Facebook. Due to the fact that many promising technical approaches fail at the market, because of a lack of user acceptance we started an exploratory study to find out criteria for a successful health social network approach, improving health promotion. Being aware that health and health related information reveal special acceptance patterns, especially when provided via Internet, we wanted to define user-centered design criteria and acceptance requirements for a health SNS.

Central findings show that neither age, gender, field of work nor private social media usage impact willingness to disclose personal health related information. Health related SNS are generally perceived positively (77%) but are more likely to be used as a source for professional information. Key issues like data security create a gap between willingness to share and willingness to consume information. Recommending a health SNS could only work if done by personal friends or the private physician. Commercial advertising or insurance company recommendations are rather distrusted.

Keywords: social media, social network sites, ehealth, acceptance, user-centred-design

1 INTRODUCTION

Today online support is no longer a big deal. On the Internet there are platforms, communities, mailing lists etc. for every imaginable topic accessible from every country in the world at any time. Among this vast amount of topics health is one of the top-scorer topic. For every disease and ailment there is a place you can go to in the “virtual world.” But not only the range of health related topics are widespread, the same breadth applies for the quality of the provided information

and services. Earlier studies about medical technology acceptance revealed that in the context of health and healthcare special demands on technology and technical applications exist that are related to trust, privacy and intimacy (Lahlou et al. 2005; Moturu et al. 2008; Scheermesser et al. 2008; Arning & Ziefle 2009; Ziefle & Schaar 2010; Ziefle & Wilkowska 2010; Ziefle & Schaar 2011).

Healthcare services provided with anonymity, ubiquity and mobility, which are the epitome of the Internet, accentuate contrasting aspects for the users. The sensitivity of health related data and Internet technology highlight the aspect of data safety and data theft. But the aforementioned properties of the Internet also lead to increased accessibility, which becomes especially relevant when providing services for a decreasingly mobile worldwide user base. Additionally the Internet offers people a feeling of protection through its anonymity, especially when the disease is related to feelings of stigmatization (e.g. STDs).

The current paper presents a research approach that is investigating acceptance aspects and design criteria in the context of health SNS. The idea presented in this paper is based on the assumption that applying a user-centred approach from the beginning could avoid misguided and superfluous products in the field of SNS to guarantee a consideration of user-diversity for universal access to future products.

To work out the special character of health the paper is structured as follows: Section 1.1 gives an overview about a range of different health related applications and services on the Internet. Furthermore a definition of health SNS is specified. Afterwards Section 1.2 points out the special character of acceptance in the context of medical technology. Section 2 contains the questions addressed in this research. The study's methodology is presented in Section 3, including a presentation of: variables (Section 3.1); questionnaire instrument (Section 3.2); sample characteristics (Section 3.3). The central results are presented in Section 4. And finally the paper is completed with a discussion of the studies central findings and limitations (Section 5).

1.1 Health affairs in the Web 2.0

Since the development from Web 1.0 to the so called Web 2.0 health topics increased enormously within this domain (Boyd & Ellison 2007). At least the special character of Web 2.0 with its facilitated participatory information-sharing, user centred design and its collaboration on the World Wide Web (O'Reilly 2005) paved the way for a mutual exchange of information by users.

The central problem within health affairs in the Internet is the broad range of products, users and topics as well as a divergence of quality. Hartman et al. are differentiating at least nine different technologies that can be used for health related exchange of information in the Internet (Hartmann et al. 2011). The list of Hartman et al. ranges from *wikis*, that are web pages which can be structured or completed by everyone who has access to the current page (Ward 2006) over *blogs*, *social bookmarking* and *tagging*, *web 2.0 search* and *social search*, *RSS Feeds*, *social communities*, *evaluation and reputations systems* up to *online social gaming* and *virtual worlds*. Each application allows action related to health within the Internet. In the following the focus of our research is set on health SNS, which are defined for our use case in the following section.

Health social networks as a special use case

The focus of interest in this research is set on health SNS and their potential benefit. There is no unique definition of SNS in general and health SNS in particular. As presented in Section 1.2 we are confronted with a number of different technologies and applications that are gathering under keywords like *social media*, *social software* and/or *Web 2.0*.

Making the subject of this research more precise, we define social media as online social

network sites. According to Boyd and Ellison (2007) SNS are defined as

“web-based services that allow individuals to (1) construct a public or semi-public profile within a bounded system, (2) articulate a list of other users with whom they share a connection, and (3) view and traverse their list of connections and those made by others within the system. The nature and nomenclature of these connections may vary from site to site (Boyd & Ellison 2007).”

In the case of health SNS – health relevant topics are the constitutional topic that connects participants, although the individual motif and the specific subject may differ.

1.2 (Medical) Technology acceptance and acceptance of social networks

(Medical) Technology acceptance

Former studies revealed that the old technology acceptance models are inapplicable to analyze medical technology acceptance. Established Theories like Technology Acceptance Model (TAM) (Davis 1989) and the Unified Theory of Acceptance and Use of Technology (UTAUT) (Venkatesh et al. 2003) were primarily developed for the acceptance of Information and Communication Technologies (ICT) which were basically focused on the job context. The central aspects that generate technology acceptance in the context of the TAM were the perceived ease of use and perceived usefulness of the respective technologies (Davis 1989). The advancement of the TAM the UTAUT additionally included personality traits like age and gender as acceptance influencing aspects (Venkatesh et al. 2003). But modern medical technology generated new demands: The rapid improvement and development in the branch of medical technology in the last decade transferred medical technology in an increased measure into the home environment. The combination of modern ICT and medical technology supported the so called electronic health sector (ehealth) which combined with Ambient Assisted Living (AAL) components supports the supply of old and frail people in the home environment (Calero Valdez et al. 2009; Calero Valdez et al. 2010). These new forms of healthcare are principally based on the Internet as a provider of data, information and communication. Unlike the parameters in the job context medical technologies and information reveal their own demands: Aspects like trust, privacy and security as well as gender, age and technical expertise are playing a central role (Ziefle & Röcker 2010; Ziefle & Schaar 2010; Ziefle & Wilkowska 2010; Schaar & Ziefle 2011; Wilkowska & Ziefle 2011; Ziefle & Schaar 2011).

2 MAIN FOCUS OF THE STUDY AND QUESTIONS ADDRESSED

The current study basically addresses five central questions:

- (a) What information do persons want to disclose on health SNS?
- (b) What are the most required functions?
- (c) What are the most important characteristics for a health SNS?
- (c) Which general associations dominate the attitude towards health SNS?
- (d) Do users characteristics influence the attitude towards health SNS?

Generating an answer to these questions should be a first step for the definition of a general health social network approach.

3 METHODOLOGY

The main goal of this study was to find out first general user demands of health SNS. To reach a large number of participants and to take diversity into the group (potential) health SNS user, the questionnaire method was chosen. The questionnaire was delivered electronically. Before distributing the questionnaire it was revised by a sample of differently aged adults. Working on the final version of the questionnaire took about 20 minutes. In the following sections the design and sample of the study is presented: Section 3.1 presents the central variables of the study. Section 3.2 contains a description of the questionnaires' design. Section 3.3 presents the sample of the survey to work out the character and characteristics of the sample. An effort was made to keep the methodology similar to earlier research (Calero Valdez et al. 2012).

3.1 Variables

As *independent variables* we have chosen the participants age, gender and self-reported health status as well as field of work and expertise with social media. *Dependent variables* are an evaluation of information possibly provided via health SNS, evaluation of functions of health SNS as well as an assessment of central characteristics of such networks, as well as a pool of adjectives that could describe the character of a health SNS.

3.2 The Questionnaire

The questionnaire used in this survey is divided into four subparts: (a) demographic data and health status, (b) SNS expertise, (c) evaluation of design criteria for health SNS, (d) adjective association about health SNS.

Demographic data and health status

To get information about the participants' characteristics they were asked to answer questions about their gender, age, field of work (technical or non-technical) and health status. The health status had to be evaluated on a five-point Likert scale. Answers had to be selected out of the following statements: *I am and feel completely healthy; I have colds regularly; My chronic disease influences my life slightly; My chronic disease influences my life to a great extent; I am gravely ill.*

Social network expertise

This section asks for experience with SNS and its modalities in the form of number of *contacts/friends within the network*, as well as *the place of usage* and the *number of regular interaction to the contacts/friends within and out of the network*.

Evaluations of design criteria of health social networks

To gather more information about design guidelines for health SNS Section 4 c contains the evaluation of design criteria. In this context we asked for (a) *the profile information a potential user would disclose*, (b) *desired functions* as well as (c) *importance of special characteristics*.

(a) The profile information are including: *name, last name, date of birth, common interests, profile image, diseases, medical fields of interest, health relevant data*. According to the different information the participants had to evaluate the degree of visibility. The rating scale contained: visible for: *nobody, my contacts, everybody*.

(b) Out of the following functions the participants were asked to pick those they would like to have in a community: *common information about diseases posted by medical staff, common information about diseases posted by community members, individual forums on diseases and disease related problems, self-help forum, chat with medical staff, chat with other community members, messaging function, non-disease-related forums, interest and thematic search for other community members, common search function within the network, diary for health parameter, diary for daily support with e.g. calorie calculator, diary for personal well being.* In this context multiple answer were allowed.

(c) The evaluation of the networks characteristics were addressed by the following items: *data security, control of articles through medical staff, code of behaviour, no advertisement, special time slots for conversation with medical staff, attractive design, user-friendly design.* Each item had to be evaluated on a six-point Likert scale from 1 (very important) to 6 (very unimportant).

Adjective association

The last task of the questionnaire was a selection of positive and negative attributes that were taken from a former focus group discussion about SNS. These attributes were: *useful, useless, exciting, boring, secure, insecure, suitable for daily use, impractical, connecting, isolating, interesting, superfluous, valuable, simple, complicated, practical, untrustworthy.* The participants were instructed that three replies were possible.

3.3 The Sample

Demographic data

The questionnaire presented in Section 3.2 was answered by a total of 53 participants in an age range from 19 years of age up to 65 (M=34.3, SD=11.9). The sample reveals a gender distribution of 34% (N=18) male and 66% (N=35) female participants.

The educational level of the sample is quite high: Over 70% of the sample reported to have completed their university education (67.9%; N=36) or PhD/habilitation (5.7%; N=3). According to the character of the profession (technical vs. non-technical) we can reveal, that 41.5% (N=22) have a technical background and 57.4% (N=31) a non-technical.

Health status

In terms of the health status we can report that the majority of the sample stated to be completely healthy (73.6%; N=39). Further 13.2% (N=7) reported to suffer from colds frequently. 11.3% (N=6) are affected by a chronic disease, which has no strong influence on daily life. Only one participant is affected by a chronically disease that influences his life enormously.

Social network expertise

76.3% (N=29), of the of the sample confirmed to use a form of SNS. Regarding the question where they use social media we reveal that the majority uses social media at home (83.7%) as well as at work (55.8%) Followed by on the run on Smartphone or notebook (Figure 1). Most participants reported to use Facebook as their main SNS (69.7%).

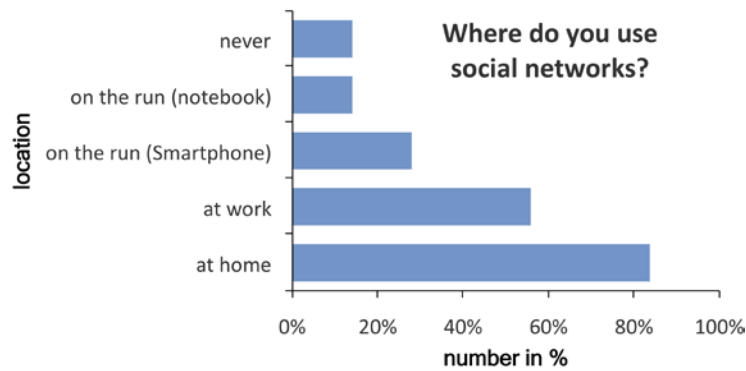


Figure 1 Location of social network usage (multiple answers possible)

In the context of interacting within the pool of SNS friends we can report that the majority of the sample only has regular contact to 10% of their friends list, within the SNS or out of the SNS.

Interactions of independent variables

Bivariate analysis of correlation reveals, that there was a strong effect of age on the usage frequency of social networks ($r = .452$ $p = 0.02$ $1 - b = .913$) as in that older users use Facebook less frequently. Gender in this sample has a strong effect on the field of work. A Chi-square test reveals, that females tend to work in non-technical jobs, where males work in technical jobs ($\chi^2 = 14.767$, $df = 1$, $p < 0.000$ $1 - b = 1$).

Summing this section up, we can state that we have a healthy sample, which is distinguished, by a quite high level of technical expertise and SNS usage.

4 RESULTS

Results in this study have been analyzed with bivariate correlation analyses (Pearson's r), chi-square tests, t-Test and ANOVA with a significance level set at 5%. For ordinal-scaled variables Spearman's r was used for correlation analysis. Where possible Type-2-Error probability b is reported as power ($1 - b$).

4.1 SNS profile information

The willingness to disclose personal information on a health SNS is relatively low. No single information item was mentioned more than 10 times ($N = 48$) with a visibility to a public audience (see Figure 2). Customizable visibility changes this willingness drastically but only for certain information items. Both parts of the name, profile picture and date of birth are more likely to be shared if the audience is selectable by the user. Nonetheless most users are not willing to disclose medical information on a health SNS.

Almost no trait of user characteristics (age, gender, health status, field of work, social media usage) shows any significant differences in mean for desired disclosure of information (age: ANOVA $p > .313$; gender: t-Test $p > .405$, health status: ANOVA $p > .105$; field of work: $p > .189$, social media usage: ANOVA $p > .304$; all reported significance values are minima for the most significant item). The only item that shows differences in means is "diseases". People that work in a field of technical work are more likely to disclose disease data (t-Test: $T = 2.071$ $df = 46$ $p = .044$ $1 - b = .90$). ANOVA analysis also showed that people that use Facebook more regularly are more

likely to disclose their first name ($p < .033$, $1 - b = .952$).

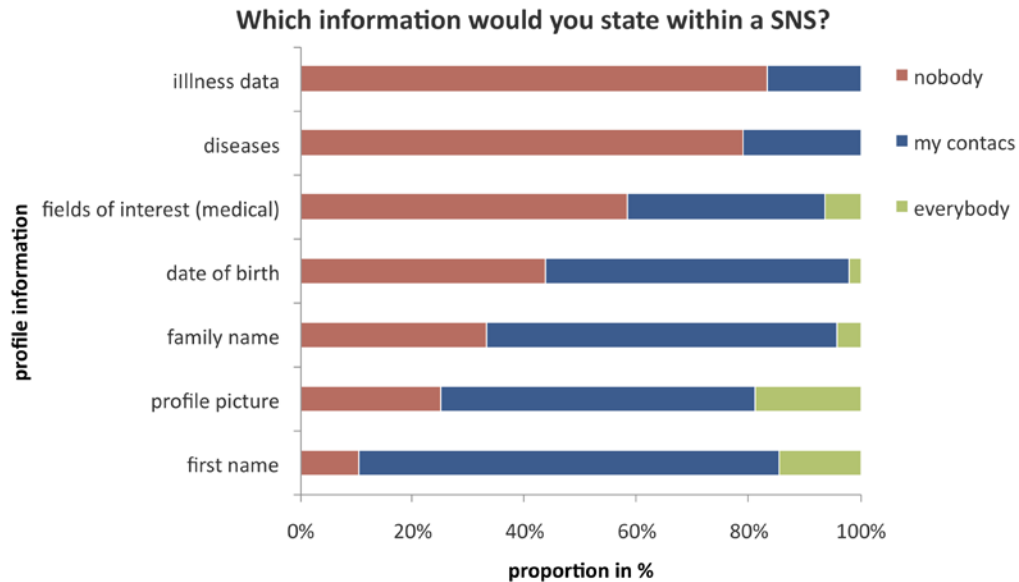


Figure 2 Willingness to disclose personal information to different audiences on a health SNS

4.2 Desired functions

The low willingness to publicly share health related data is also reflected in the desired functions for a potential health SNS. The three most important functions were “*general information about diseases through medical staff*”, “*individual disease and special interest forums*” and “*chat with medical staff*” (see Figure 3). The least important functions were “*non-disease oriented forum*” (N=6), “*diary for reporting well being*” (N=8) and “*diary for medical data*” (N=11).

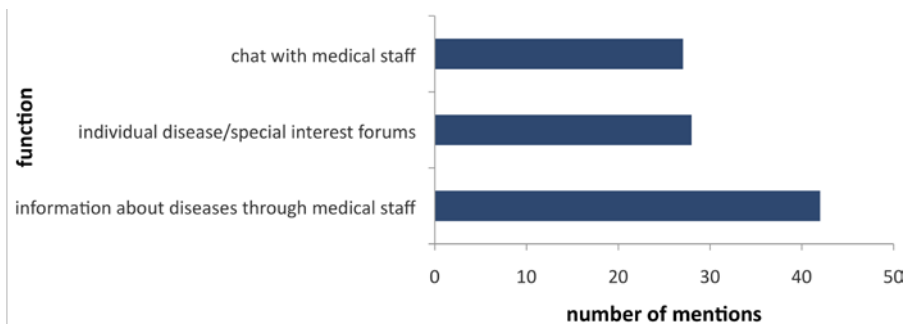


Figure 3 Most desired functions in a potential health SNS

Characteristics that a potential health SNS should incorporate are most importantly data security, medical accuracy and user-friendly design. Members of this sample rated data security as the most important characteristic for a potential health SNS (see Figure 4).

Both desired functions and community characteristics show almost no dependency on user characteristics (age, gender, health status, field of work, social media usage). Only the wish for a medical data diary is higher in the group of people that work in technical a job (t-Test $T = -4.269$

df=51 p<.001 1-b=.999) than for those within a non-technical job.

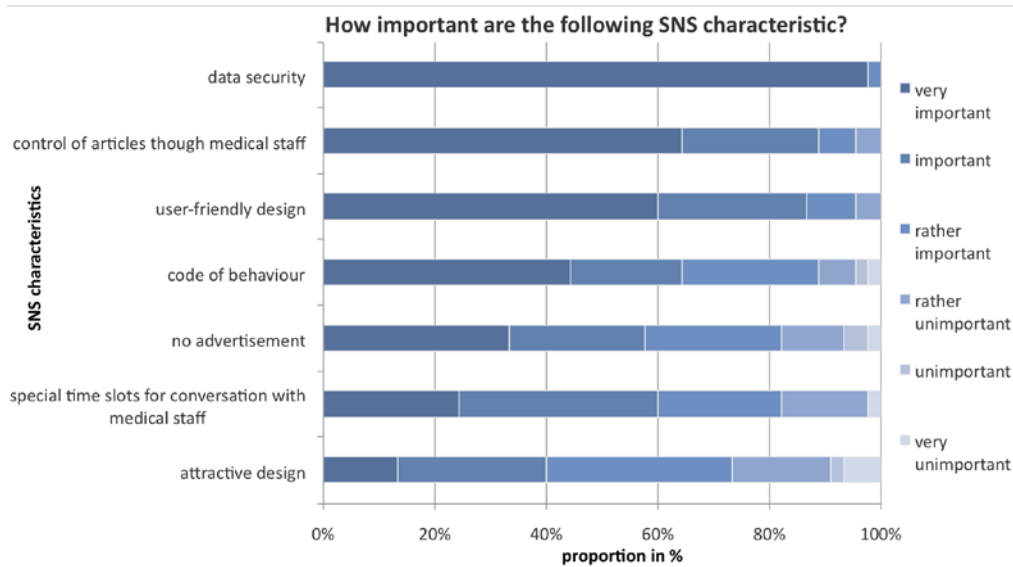


Figure 4 Importance of characteristics in a potential health SNS

4.3 Interactions of attributes

In order to understand what attributes participants associate with medical SNS nine attributes as well as their antonyms were presented within the survey. Participants could tick a box if they agreed that the said attribute would fit a description of a medical SNS. The attributes interesting, useful, practical and insecure were those that were mentioned most frequently (N = 20, 18, 16, 10). Out of 113 selected attributes 87 were of a positive connotation while only 26 had a negative connotation (see Figure 5). Given that each participant could only select maximal three items, 29 selected three items, nine selected two and eight selected only one item. All chi-square tests showed no significant interaction if corrected by Yates for all user characteristics.



Figure 5 Bubble graph of associated attributes. Larger circles mean that more participants associated this attribute with a medical SNS. Distance of circles relates to co-occurrence. If two attributes were selected by the same participant, they are closer together.

5 DISCUSSION AND LIMITATIONS

The results of this study suggest, that German users put high emphasis on data security. Even in the expectation that a health SNS would be useful, interesting and practical, data insecurity plays a dominant role in the attitude towards health SNS. In particular sharing or disclosing health related data or information is not desired. Nonetheless users like to consume professional guidance and benefit from other users sharing their information. This might reflect a typical German perspective, as in Germany data security is regarded as very important.

In order to avoid this conflict other forms of ehealth-technology could be implemented as support for disease stricken patients. Ambient assistant living or video conferencing with your personal doctor could benefit from this attitude.

The sample in this study is rather small and of high education. This might lead to a skewed view especially because all of the participants were of the “lurker” type and not contributing to any health SNS. In future research different ways of increasing trust should be examined. Especially standardized quality seals of data security or government control should be regarded.

The survey was constructed in a rather abstract fashion, as no concrete implementation of a health SNS or prototype was presented or familiar to the participants. This could have lead to filling information gaps with prejudices guided by horror scenarios. In many prior cases acceptance of SNS where higher after usage when the user could reap and feel the benefits of the service provided.

In this study we also assessed locus of control and technical expertise, but both did not yield any significant outcomes. This might also be due to the selective highly educated sample.

Maybe the time has not yet come for German health SNS. Interestingly users would try a service if friends or the personal doctor recommended the service. Health insurance companies should refrain from recommending usage, as they are disregarded as commercial advertising.

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