E-health

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ABSTRACT

E-health refers to information and health services delivered via the Internet or related technologies. Whilst usage statistics suggests that the internet is an e-health success story issues surrounding quality of information, user interaction and personalization raise important questions for researchers and designers alike. The move towards ubiquitous computing accentuates these concerns and highlights the relevance of trust, privacy and disclosure to the debate. This one-day workshop will bring together an interdisciplinary group of researchers and practitioners to discuss how the fields of human computer interaction and applied psychology can address the issues raised by the growing domain of e-health.

Categories and Subject Descriptors

H.3.3. Information search and retrieval H.3.5 Web based services I.2.1 medicine and science

General Terms

Design, Human Factors

Keywords

e-health, trust, disclosure, privacy, health technologies, Internet, Ubiquitous computing

1. INTRODUCTION

E-health is a term widely used by many academic institutions, professional bodies and funding organizations. Rarely used before 1999 it has rapidly become a buzzword used to characterize almost everything related to computers and medicine. E-health can encompass a wide range of technologies (Internet, interactive television, personal, digital assistants, CD-ROMS and ubiquitous computing - Ubicomp) a range of health services and information types (family practitioner's surgeries, public settings, consultations, decision making,) and a range of different stakeholders (medical professionals, business, patients and carers).

E-health has a large remit and currently covers a number of large scale projects, for example the UK National Health Service's Connecting for Health programme which aims to provide improved patient care through the implementation of IT services.

At the individual level, more than three quarters of all Internet users have searched online for health related information [1]. Yet less than half of the medical information available online has been reviewed by doctors [2] and a systematic meta-analysis of health web site evaluations noted that 70% of the studies reviewed concluded that quality is a problem on the Internet [3].

Despite its unregulated and often unreliable nature, the Internet is rapidly becoming a new "object of trust" [4]. Research indicates that internet users' rate trust as an important issues within the health domain [5]. They are interested in health advice which is independent and impartial and want websites to be easy to use [1]. Recently health consumers have been turning away from more regulated sites (i.e. those run by government bodies) and towards more personalized sites, often maintained by interested individuals [1]. Users are keen to explore other patients experiences online [6] exchanging advice, empathy and support. The rise of social networking sites such as MySpace and facebook facilitates the disclosure of personal health information but also highlights issues surrounding computer mediated discourse in terms, for example, of identity. The vision of ubicomp encompasses always on communication and seamless access to information. This has enormous implications for e-health. Systems that not only store health data but continuously monitor and communicate health status and hospitals that are primed with up-to-date information the moment the patient arrives. The exchange of health information and advice via any technological medium raises important legal and ethical issues. Inappropriate data exchange would surely be a major violation of privacy? What do people understand about security issues associated with certain e-health applications? We need to understand more about issues such as trust and disclosure and their relationship with e-health.

1.1 Trust in e-health

The literature suggests that a number of different factors are important in influencing peoples' decisions regarding trust in an e-health context. Firstly they may be influenced by the look and feel of the site – trusting, for example, those sites rated high in visual appeal and mistrusting those sites with poor visual design or with unprofessional errors. Secondly, they may be influenced by the branding of the site or by presence of familiar images or trusted logos. Thirdly, they may be influenced by the quality of information available on the site, trusting those sites

with greater perceived expertise, and fourthly, they may be influenced by the extent to which the advice is personalized to the individual – i.e. the extent to which the advice appears to come from and be directed to similar individuals (i.e. those with a shared social identity).

The staged model of trust [6] offers a way of reconciling the differences in the literature. Their model suggests that three phases are important: a phase of initial trust followed by a more involved exchange which then may or may not lead to a longer-term trusting relationship. If one considers trust in this developmental context then some of the findings in the literature make more sense. In particular, consideration of a developmental context helps to reconcile the tension between those models of trust which suggest that it is a concept grounded in careful judgment of institution and process factors such as vendor expertise and experience, process predictability, degree of personalization and communication integrity and those models that suggest trust decisions depend much more heavily on the attractiveness and professional feel of a site.

Although trust decisions are underpinned by a number of different factors the internet still provides an opportunity for individuals to make their own trust judgments. By contrast in a ubicomp context, “mutual trust is crucial for ubiquitous devices, which must share information and work together to present an unobtrusive interface to users” [7] – in other words, people will not be able to make their own individual trust judgments but will need to hand these decisions on to intelligent agents. This is borne out of necessity as people would otherwise find it impossible to cope with the volume of information exchanged and the demands on their time for moment-to-moment trust decisions. Modeling trust preferences in these networks is a more complex task. The mechanisms that drive trust up or down need to be explored further and some authors have highlighted the importance of constructs such as forgiveness and regret in the framework [8]

1.2 Disclosure in e-health

As people engage with e-health material they are increasingly exposed to other people’s experiences and stories. Health consumers have to make disclosure decisions throughout their interaction with e-health material and services. How do people decide whether or not to register on a particular website? How much of their personal information are they prepared to disclose to the site and to other users? Social networking sites make it easier to disclose personal information but are people always sure about what information they are disclosing and to whom? What types of privacy, if any, are people seeking to protect in an e-health context? Within a ubicomp context there are already the very beginnings of a new research literature in which we can see ways we can model individual preferences in respect of releasing sensitive health information to a network of trusted agents. Work by Little et al [9] in a number of ubicomp domains including health seems to indicate a complex pattern of disclosure relationships whereby people engage with different trusted agents (doctor, partner, friend, employer),

potentially disclosing personal health information. We need to understand the ways in which people inadvertently ‘leak information’ as well as consciously try to regulate the information ‘they give out.’

2. WORKSHOP PROCEDURE

The workshop will provide a forum for those interested in e-health and in particular but not limited to issues of trust, disclosure, privacy and security within the e-health context. The one day workshop will consist of a mixture of individual presentations and group based discussion.

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