

## **Use of the Internet by Health Professionals and Consumer Support Groups: a case analysis**

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### **ABSTRACT**

*This paper outlines case study research with “Eye Believe” a support group for patients who have had an eye removed usually (but not exclusively) due to ocular melanoma (cancer of the eye). It is a participative action research (PAR) project. The aim is to adopt a user-centric socio-technical approach to developing an online community to offer information and support to the group. The project will draw upon theories of knowledge creation and management through socialization, user participation in a health service context and the sociology of technology. In its initial stages the research was explorative. However, a conflict of interests immediately arose between the support group members and the health service representatives. Through this conflict it is anticipated that the research will now adopt a Critical Social Theory (CST) approach in aiming to empower the member’s of Eye Believe through their online community.*

Keywords: Information systems in healthcare, Virtual health communities, Internet and health information, Critical Social Theory Research.

### **INTRODUCTION**

This project is funded by a ‘seedcorn research grant’ awarded by the Research Institute of Business and Management, Manchester Metropolitan University. This project has developed out of research into consumers’ uses of the internet in commercial activity carried out towards a PhD at the University of Salford. Research results suggest that the internet does not empower consumers in commercial interactions (McLean and Blackie, 2004a), (McLean and Blackie, 2004b). However, participants frequently recounted empowering experiences of using the internet to find information and support for health related issues.

It is well established that health information is one of the most frequently sought topics on the internet (Nicholas et al. 2003). However, most of the research to date focuses on the health consumer’s use of the internet to retrieve health information provided by health professionals or service providers such as NHS Direct Online, MedicDirect, or even independent alternative therapists. This top down technologically determinist approach fails to capture the truly empowering essence of the internet as a facilitator of consumer connectivity. Through online communities a unified body of health consumers with a common and specific interest are coming together, sharing experiences, offering support and even taking collective action (Armstrong and Hagel III, 1996).

This paper outlines case study research with “Eye Believe” a support group for patients who have had an eye removed usually (but not exclusively) due to ocular melanoma (cancer of the eye). The group is based at North East England Health Trust and this research proposal has the support of both the consultant in ocular oncology and the liaison staff nurse. The catchment area for the group extends from South Yorkshire up to the Scottish Borders, and so an online support service would be an effective way to manage resources. A website has been attempted by the group in the past but this is of a limited scope and is out of date. The group is about to begin developing a community website as a response to a perceived need for information and support amongst the group (a technologically integrationist approach.). This initiative has the full support of the clinicians and aims to take a

collaborative (service providers collaborating with service users) and co-operative (service providers and service users collaborating with researchers) (Heron and Reason, 2001) approach.

Given this, the research will inform both health service providers and managers for future consumer support initiatives. Theories of the social construction of knowledge (through communication) (Demarest, 1997), (McAdam and McCreedy, 1999), and participative IS design will provide a conceptual basis for the research. Participative design theory has seldom been applied to health service provision. This research could both draw upon and inform participative and cooperative IS design theories specifically for the health sector. In observation of the process of constructing the website, and the interactions between service providers and users, theories of technological determinism and constructivism (Bijker, 1999) will be drawn upon.

## **RESEARCH OBJECTIVES**

The aim of this research is to explore the evolving phenomenon of the use of the internet by health service users and to investigate the relatively neglected issue of how the internet is integrated into existing information and support systems. It will provide a unique insight into the uses of the internet by a specific group of health consumers and health professionals as they construct and participate in their online community. The theoretical lens will be that of Wenger's communities of practice. Communities of practice exist in order to "create, expand and exchange knowledge and to develop individual capabilities" (Wenger, 2000). The purpose of EyeBelieve's online community is to enable members of the group, including both customers and providers of the health service to create, exchange and expand knowledge of the service offered to people in need of this medical procedure. Further, it seeks to assist and support EyeBelieve members in post-operative daily life developing individual capabilities. Similarly, individual capabilities will be developed in terms of expanding professional knowledge for the clinicians and service managers.

The problem situation therefore becomes to explore how online support groups be used by health service providers and users in health care provision and post treatment support?

This can be further delineated in the following research questions:

1. Are health professionals' and health service consumers' requirements of an online support group aligned?
2. How can health professionals / health service consumers' benefit from the use of an online support service?
3. Is the internet a useful and effective method of customer support in health services?
4. What are the design issues in creating a website for a health support community?

The objectives emerging from the research questions are:

1. To further the research into the use of health information on the internet.
2. To participate in (through Participative Action Research PAR) the process of setting up a support service for health consumers.
3. To explore the requirements of health service consumers and professionals for an online support community.
4. To understand and present the benefits and problems experienced in the use of an online support service by health service consumers and professionals.
5. To provide HCI guidance for website design to independent support groups.

This critical study aims to understand the adoption and use of the internet in health support services and to uncover emerging and transferable theories (Lincoln and Guba 2000), (Easterby-Smith et al. 2002).

## **METHOD**

Within this case study, the researchers will adopt a participative action research (PAR) approach and will attempt to describe the actions, events and decisions taken during the course of the development, implementation and use of the site. The Case study approach is a well recognized immersive method for conducting an in depth study such as this (Yin, 1994). Initially a focus group will be held at one of the meetings of the *Eye Believe* group where the research project will be presented and experiences and requirements of the group explored. A website will be developed based on the group's requirements and suggestions. The site will be demonstrated to them at a later meeting. In an iterative process any amendments to the design and content will be addressed.

Following the launch of the website, usage will be monitored and individual experiences of using the site (or reasons for neglecting to use the site) will be explored through interviews and focus groups. Observation and interpretations of discussion forums and message boards will contribute to the interview data collected to assist in the evaluation of the effectiveness of this medium for health related support.

At this early stage in the research it is difficult to offer much detail on the action research cycle. Action research is an emergent and iterative process in which the cycle or spiral of understanding increases as understanding of the phenomena under study unfolds. Each stage of the design of the website and subsequent meeting with the community will undergo a critical reflection which will inform the next stage of the research.

## **CONTRIBUTION TO KNOWLEDGE**

The outcomes of the research will be of use to health professionals and policy makers informing future adoption of the internet into current practices, and to others with an interest in organizational use of online communities, particularly within the not for profit and voluntary sector. In drawing upon the theories of CRM and Knowledge Management, this research will contribute to management concepts in those areas as well as extending research in the field of the sociology of technology. On a more pragmatic level, the issues arising from the iterative and participative design of the website will inform future practice.

## **PROGRESS TO DATE**

As this research began the *Eye Believe* group widened their membership to include those who have lost an eye for reasons other than cancer. The liaison staff nurse pointed out that this has increased the number of members and widened the age range of the membership of the group. The website now needs to cater for children, adults and older adults.

Significantly, electronic discussions were held with the Information Systems (IS) representative of the health trust to explore the possibility of the trust hosting the website. The response was predictably technologically determinist, the IS representative stating that if the trust was to host the site he would have to *design* the site. He offered to contact the liaison staff nurse to determine suitable content. A request from the researcher that an *Eye Believe* focus group be held to inform the content remains unanswered. It is important to note that this was not the view of the liaison staff nurse who maintained that the group must take control of the website.

This interchange was conveyed to the chair of *Eye Believe* who expressed his concern at the content of the website being removed from the sphere of control of the group. He commented that the website would be of no use if members were told what they could and couldn't include on the website. The first conflict between providers and users of online health support became apparent. This research proposes that the conflict arises from a number of issues:

1. Legal issues relating to the liability for website content
2. The tradition of lack of user involvement in IS development
3. The hierarchical status and issues of power in the health service provider / user relationship

Following this, it was decided that the group would most benefit from an independent website where clinicians could be invited to contribute or respond to requests for information or support. The domain name [www.eyebelieve.org.uk](http://www.eyebelieve.org.uk) has been registered and a focus group meeting is planned for the end of March 2005 to

discuss and negotiate content for the site. Some background research into design issues has been conducted and is presented in brief below.

## HUMAN COMPUTER INTERFACE

According to Spink (2001) nearly 10% of web searches are for health or scientific information. For this reason accessible health information should be a high priority for those creating, organizing and disseminating information. Further, organizations have a legal obligation to implement a website that is accessible to those with disabilities. This is referred to as accessibility legislation as outlined in the Disability Discrimination Act 1995. Although no format for an accessible website has been agreed upon the World Wide Web Consortium (W3C) does provide a set of guidelines which can be executed to ensure web sites are compatible with people's disabilities.

Chaffey (2004) identifies some of the complications faced by visually impaired users. Some users may need to enlarge the text size on a website, a feature facilitated by many web browsers. However, due to how the website is written, browsers may be unable to facilitate users in changing the text size. Other users may only be interested in text content, as opposed to graphical content, so as to enable text recognition technology to read the webpage. Nevertheless, because some websites use graphical links without comment tags the text reader is unable to interpret the text, therefore, limiting visually impaired users accessing the website. It is for reasons such as these that alternative text versions of the website should be made available to cater for all users.

Chaffey outlines three ways legal compliance can be achieved:

1. The lowest cost method commonly adopted by small and medium sized organizations is do it yourself by monitoring online law specialists and ensuring the website meets the requirements.
2. Medium to large sized organizations can contract a lawyer to continually audit legal requirements.
3. Large companies may have a department dedicated to advising on these issues.

However, literature in the form of simple guides to enable the independent support group such as *Eye Believe* to meet these requirements is sparse. Documentation of the process of constructing this website will address this gap.

## CONCLUSIONS

This research in progress is in its very early stages. However, a number of issues for consideration and concern have been highlighted. One issue which will have a significant impact on the design of this study is the conflict of interests that immediately arose between the support group members and the health service representatives. Research such as this frequently begins as an explorative, interpretive study whereby the researcher "stumbles" across a conflict of interests or challenge to the *status quo* (McLean & Nolan, 2004). This is precisely the case in this project, and it is anticipated that the research will now adopt a Critical Social Theory (CST) approach in aiming to empower the member's of Eye Believe through their online community. The aim is to emancipate this group of health service customers in assisting them to take collective control of their health information and support needs and provision.

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