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GAPS BETWEEN INTENDED AND ACTUAL USE

- TURNING PROBLEMS INTO OPPORTUNITIES IN HEALTH INFORMATICS

ALF WESTELIUS
Information & Systems Management
Dept. of Computer and Information Science
Linköping University
Sweden
alfwe@ida.liu.se

MATS EDENIUS
Centre for Information and Communications Research
Stockholm School of Economics
Sweden
mats.edenius@hhs.se

Abstract

There has been a rapid increase in interest to utilise the www for communication between the healthcare sector and the public. However, the potential seen by proponents is far greater than the actual achieved use. Some proponents may have overrated the potential, but in many projects there is a gap between the actual and possible achievement. In this article, we explore how the gap between envisaged and actual use can be closed, drawing on published healthcare management and health informatics studies, Actor-Network Theory and using two case studies of Swedish health informatics services. We identify two important factors for closing the gap. The first is an attitude towards unintended use as a source of further valuable adoption, rather than as behaviour to be corrected. The second is the identification and promotion of networks that support the use of the e-service, rather than focusing too narrowly on the e-service itself.

Keywords: health informatics; e-health, unexpected use, misuse, feedback, unsolicited user feedback, actor-network theory, translation, imaginator

1. Introduction

IT promises to become an important aspect of healthcare management. For decades, visionaries and enthusiasts have tried to extend the application of IT in healthcare. At present, it is commonly believed that IT is useful to healthcare, and that the potential is to a large extent untapped. Medical informatics associations have been established across the Western world, and journals dealing with medical internet research indicate the interest in exploring how the Internet and the www is, and can be, gainfully employed in healthcare, and in particular in the communication between the public and the healthcare providers [Taylor and Leitman, 2002; Craigie et al., 2002]. However, the potential seen by proponents is far greater than the actual use that has

been achieved. It could be argued that there should be a gap; the envisaged use should always be greater than the actual, otherwise there is no dynamism and development. A gap could also result from unrealistic expectations about the help that could be achieved by the use of IT. If these two points are indeed accepted, it is still probable that money and other resources spent on IT support in healthcare, as in other areas of the economy, could result in more useful and used applications than is currently the case. In this article, we explore how the gap between the envisaged and actual use can be closed.

Building an ambitious website can be very expensive, but setting up an elementary homepage has an almost negligible cost, both in terms of money and the knowledge and time required. Because of this low entry barrier, much of the early development has involved local initiatives by enthusiastic individuals or exploratory attempts by single institutions. However, as healthcare in Europe is one of the major public sector preoccupations, combined with the spread of the concept of eGovernment, this has led governmental agencies to attempt to co-ordinate local efforts. One such attempt is Vårdguiden, the Stockholm County Council's web portal for healthcare and telephone consultation. There are also focused, ambitious, non-governmental initiatives, such as the Swedish Cancer Society's cancer information and support service, which uses a combination of the web, email and the telephone. These two initiatives are subject to investigation in this article.

Feedback is essential in developing e-services. Van der Lei [2002] explores the need for feedback in developing appropriate use of clinical records. His discussion focuses on the use of ICT in the medical profession; we study its use when the public are involved. Individuals setting up a health informatics service possess some ideas regarding the services it should provide. However, users will have, or develop, other ideas regarding what services the new channel offers – or should offer [Randeree and Rao, 2004; Edenius and Westelius, 2004]. They will express some of these ideas as suggestions for changes, while other ideas appear as actions: users will use the e-service in ways neither intended nor anticipated by the designers. These unintended uses can be viewed as incorrect use that requires further education of users or new means of enforcing discipline in the use of the service. But they can also be used as important sources of information regarding what the public and health care professionals both require and desire. In this article, we explore the balance between these two stances towards unintended use.

Firstly, we look at medical informatics, establishing that the www and the Internet are believed to have great potential for healthcare, but that controversies do exist in the extended use of IT. Physicians and the general public can have overlapping, but also to some extent opposing interests. We then look at health informatics ventures as change projects, exploring the situation of the project manager, and placing the IT application in a context of changing use, drawing on Actor-Network Theory. By taking into consideration the importance of user feedback to the functioning of a system, it is noted that unintended use can be viewed as important feedback or, alternatively, as misuse, which necessitates discipline and further education among users. Finally, before turning to the two case studies, the notion of established and developing networks is explored. We note that a new e-service faces a number of established networks, and that the imaginator behind the e-service is likely to overrate the significance of the new e-service to its intended users. In the case descriptions, we then look for ideas regarding how unsolicited user feedback can be obtained and used to enhance further valuable adoption and use of

the application, and any conditions that exist which prevent or complicate such feedback loops.

2. Literature Review and Frame of Reference

In this section, we first review the potential and practice of the www and the Internet in the interaction between the general public and healthcare providers. We then consider writings on IT ventures as a part of organisational change. Finally, we present the frame of reference that guides our description and analysis of our two cases. Drawing on Actor-Network Theory, it revolves around the interplay between initiators and users in shaping an innovation – here the development of ICT-support in health informatics directed at the general public.

2.1. The www and the Internet in healthcare - potential and practice

Articles on healthcare management and the use of the www and the Internet tend to fall into one of two categories. One group is more model and technology oriented. The authors typically describe a conceptual or computerised model, and argue that it solves or could solve a problem, e.g. [Katehakis et al., 2001; Brennan and Strombom, 1998]. The other, more oriented towards actual practice, either builds on surveys to form a picture of healthcare providers' or patients' views and actions (e.g. [Potts and Wyatt, 2002; Sciamanna and Clark, 2002; Smith-Barbaro et al., 2001; Murero et al., 2001]) or provides case descriptions of actors whom the authors view as advanced IT users or as those who should be advanced IT users [Guah and Currie, 2004]. Not everyone studying the use of the web by specific institutions make choices of exemplary institutions. Norum [2001], for example, examined Norwegian cancer clinics' use of the web as a marketing tool, comparing his findings with the views of cancer patients regarding the web as a source of information when choosing a clinic, and he questioned the very low use of the web found among the clinics studied.

The conclusions tend to point to the potential of medical informatics and encourage the further development and application of www- and Internet-related IT in the health sector. The use is not, at present, particularly developed, but patients tend to indicate a strong interest in an increased supply. Patients who access the web find information on the web valuable and useful, but also require easily accessible, authoritative sources – preferably written or at least endorsed by their own physician. The majority of patients, who have Internet access, want to be able to communicate by e-mail with a healthcare institution and, in particular, with their own physician [Sittig et al., 2001]. Physicians, on the other hand, tend to be more hesitant [Patt et al., 2003]. The worry exists that patients will find misinformation and that more time will be spent discussing diagnoses and treatments read about by the patient, but not considered relevant by the physician in the specific case. In addition, it is believed that written communication with patients increases the risk of misinterpretation of the physician's messages [Potts and Wyatt, 2002], and – looming large – the threat that physicians will be overwhelmed by e-mail questions and requests. However, these points appear more prominently among those physicians who have not experienced Internet-based communication with patients, than among those who have, and an asymmetry also exists in the consequences for the different parties. Potts and Wyatt [2002] note that doctors in their survey report more benefits than harm for patients from the use of web-based information, but that more problems arise for themselves

and their institutions – mainly from longer consultations and unnecessary investigations. The large survey of patient-provider e-mail communication performed by Sittig et al. [2001] indicated that fears of being overwhelmed by patient e-mails were, at least so far, greatly overestimated. However, physicians' misgivings concerning internet-based patient communication can promote an overly cautious attitude to a web-service venture, which can be viewed more as a back-up insurance, rather than as a strategic venture to be forcefully promoted (cf. [Westelius, 2001]).

Gerber and Eiser [2001] found that health-related websites were in general appreciated by the public, but that whereas some individuals became "empowered" and wanted to take control of their own healthcare (sometimes to the extent that they stopped believing in their doctor and refrained from following the doctor's prescriptions), others still wanted the doctor to take decisions, and just viewed the web resources as a means of increasing their own understanding of their condition and of what their doctor had tried to tell them. Henwood et al. [2003] found a similar range of attitudes regarding informing yourself or listening to the doctor, but none of their interviewees felt that websites were the first choice for obtaining information when they felt unwell. In addition, many interviewees experienced a clash between informing themselves and talking with a doctor. It was felt that it was not necessarily of benefit to look up information yourself as it could be a source of tension and, in addition, complicate the relation with the doctor.

If the technical possibilities are compared with the reports of what has actually been implemented and used, an untapped potential for ICT use in communication between the general public and healthcare professionals with regards to informative websites aimed at the general public appears to exist. However, there is also a potential controversy. Increased use of the www and the Internet can be expected to be appreciated by the public, and possibly also increase the quality of such healthcare where patients play a prominent role. The downside is that there is a risk that these advantages will be accompanied by problems and costs for physicians and healthcare institutions.

2.2. IT ventures and organisational change

Three important roles in organisational change efforts involve those of actors (those who perform the change), owners (those who can stop the change from taking place), and customers (those who are affected by the change) [Checkland and Scholes, 1990]. In IT-related change efforts, those who are actors in the actual software implementation process often do not view themselves as organisational change actors [Westelius, 1996; Markus, 2004; Scheepers, 2003]. Although there are often visions of great changes in healthcare provision underlying IT support ventures within the healthcare sector (e.g. [LeRouge et al., 2005]), actual IT implementations tend not to be part of more overarching change initiatives. The changes appear to be expected to materialise merely because a new tool has been installed. This is similar to the stance taken in manufacturing and service companies in the 1980s and early 1990s [Sannes, 1996; Markus and Benjamin, 1997; Orlikowski and Hofman, 1997]. Although it is easy to criticise from an overall effectiveness point of view, it could make sense from the points of view of the individual actors in focussing on the part of the project over which they have some control or influence, rather than attempting to take a system's perspective which includes those of the owners over whom they have no power. Physicians are powerful, as their co-operation is typically vital. However, politicians

and civil servants in management positions can lend support to approaches that benefit the public at the physicians' expense. If they do this, it should not just be in terms of supporting an IT venture. The IT venture must be placed in context and supported by contingent organisational changes. As argued by Petri [2001], the match between incentive systems and intended uses of information systems is an important, but often neglected, area. Petri identifies a number of instances when the present incentive system actually discourages the intended use of the information system. An information system that benefits the general public while placing greater demands on physicians will not be successful unless the incentive system is adjusted to support the change.

Physicians are often viewed as customers in health informatics ventures as it is they who will be affected. There is rather less focus on the patients as they are merely receivers of healthcare – possibly improved, but still delivered to them, rather than involving them. If the process of delivering the healthcare is made more efficient, then the traditional view has been that this is an internal matter of interest for the healthcare suppliers.

A rather different perspective is one that views the patients as the great, untapped resource in a strained system. The relevant systems view is thus widened from merely looking at the traditional healthcare providers, to that where potentially active patients are included in the healthcare provision system. Physicians, nurses and other healthcare actors find their work evermore stressful. The system is typically optimised with regard to physician time. Nurses and patients are scheduled to enable the physician to work without any unnecessary waiting time. However, this view of the healthcare system has only been developed during the last 150 years in the West, to take account of the progress in medical knowledge and the increasing ability to treat hitherto incurable ailments. The trained physician has acquired knowledge that far surpasses that of the layman but the promise of IT is that it will somewhat redress the balance. It is now possible for the general literate and often also highly educated public to have rapid access to medical information designed for laymen, and acquire substantial knowledge concerning their own specific symptoms and possible remedies. This development does not match all physicians' worldview equally well. It is viewed as a threat by some physicians, a promising development by others, and by others as simply a fact which must be handled [Ball and Lillis, 2001; Taylor and Leitman, 2001]. Researchers have now begun to look at the mass of health-related websites accessible to the general public in terms of quality and trustworthiness because it is now a potentially important part of healthcare [Randeree and Rao, 2004].

Web initiatives conceived or at least endorsed by politicians have tended to place the patient more at the centre. Ventures such as the United Kingdom National Health Service website NHS Direct Online, the Stockholm County Council website for healthcare Vårdguiden (www.vardguiden.se) and the Swedish county councils' and pharmacies' health information website Infomedica (www.infomedica.se) either build on a view of patients as a potential resource in the evermore costly provision of healthcare, or view information to the citizens as an important part of democracy, empowering people to make informed choices and to be aware of what they have a right to expect from society. In either case, the primary user will be the resident / citizen / patient. The application is said to be developed to aid, support, inform or in other ways serve the resident. Patient, originally derived from the Latin *pati*, to suffer, has come to denote a person receiving care or treatment from a physician – one who is passively affected. In an attempt to take more of a prosumer stance (prosumer: a

consumer who takes an active part in production [Toffler, 1980]), people engaged in developing medical web services for the public have started to look for other, more neutral words, such as residents.

Viewing the resident as the primary user could suggest that the website will deal with the wants, needs and expectations of the residents. However, it is not evident that the healthcare providers and the actors in the projects take this perspective. It is possible that they take an expert stance, defining what the public should need, and viewing unintended use and requests for modifications as examples of misuse by uniformed users, rather than as valuable expressions of expectations and needs. This is in line with the dominant view of IT-enabled organisational change, for example expressed by Markus [2004, p.7]. "The major risks in technochange are the risks that "users" (employees, customers, suppliers, etc.) will not use the technology, that they will misuse it (that is, use it in ways project sponsors did not expect), or that they will use the technology without capturing the expected benefits." The emphasis is on the expected, the initiator's plan regarding how the technological initiative should be used. The proper action, given the interpretation that unexpected use is *misuse*, is to educate the users or restrict the possibility of using the application in unintended ways.

2.3. Initiators and users, Actor-Network Theory and e-health ventures

Actor-Network Theory (ANT) includes a number of traits that lend themselves to the exploration of IT-related organisational change projects where many actors have a large degree of discretion concerning their actions [Latour, 1996a; Walsham, 2001; Gäre, 2003]. On the one hand, ANT emphasises that computer programs and accompanying work routines embody "inscriptions" that can direct ones work in similar ways to those that other (human) actors can affect it. These inscriptions are formed by those designing and building the applications. On the other hand, power over the use of the application does not lie with the designers and initiators. Each new actor chooses, to some extent, whether to subscribe to the network, and typically "translates" the capabilities of the artefact, the non-human actor, to the actual situation in which he or she will use it. Those wishing to promote the use of an artefact must then sell their inscription to others, while attempting to not only enrol others for the network but also to keep the inscription unchanged so that the network still serves the original goal. An important form of strengthening an actor network is to link it to existing networks [Latour, 1996b]. Efforts to enable the network to grow can give rise to counter-programs and counter-enrolment. This is the concept of Actor-Network Theory used in this article. As John Law notes on his ANT website, "*actor-network is not a single orthodoxy, a fully consistent body of writing with its holy scriptures. Indeed, the most creative texts are often those that change and rework its preoccupations and its tools - or which combine them in one way or another with those of other approaches with which it is in dialogue.*" [Law, 2004] This is in keeping with the central tenet of ANT, that the spread of an idea, an inscription, in a growing network of actors will continuously change the original idea through the translations of it that the new actors make.

In terms of a manager of a healthcare website or other Internet-based e-service, an ANT approach would entail focusing on increasing the size of the network of people using and supporting the service, while paying heed to how the translations

new actors make change the original intentions. Two different goals could be envisaged. One of which is to attempt to retain as stable and unchanged an inscription as possible by educating or disciplining new actors whose translations diverge noticeably from the original intentions. The other is to pay heed to the translations, attempting to catch and incorporate interesting new ideas, and feed them back into the design of the artefact thus increasing the spread of the new interpretations within the existing network. This second approach is closely related to drifting, the inescapable and probably useful changes that an IT application undergoes over time, as different actors and changing conditions affect it [Ciborra, 2000]. We are not proposing that drift can be completely controlled, but rather that mindful attention to possible drift can be useful.

2.3.1. Views on user feedback and system quality

Those individuals setting up a health informatics service will have some ideas regarding the services it should provide. However, users will not restrict their use to these ideas. They also have, or develop, other conceptions of what services the new channel offers – or should offer. [Edenius and Westelius, 2004] This will result in straightforward comments as to what additional services should be offered, additional comments supplementing the intended use of a specific service, but also innovative (and unanticipated) use of the existing services. Examples include using the comments field in the appointment request form for a message such as ”I do not want an appointment. I just wanted to say thank you for a warm and comforting reception last Wednesday!”, or a direct health care question expecting consultation in writing instead of an appointment. Another example is how patients using a “nurse-on-telephone” service start discussing their worries about how their ailment affects their relatives, or how the money paid in taxes is actually used for health care.

These unintended uses can be viewed as noise or unwarranted incorrect uses that require further education of users and require new methods to enforce discipline in the use of the service. But they can also be used as important sources of information regarding what the public needs and wants – what are their concerns and worries, what services would they appreciate?

It is interesting to note that the Quality Criteria for Health Related Websites from the Commission of European Communities (http://www.jmir.org/2002/3/e15/) do not include ideas regarding user feedback among the quality criteria. However, the Swedish UsersAward user-centred software certification program (http://www.usersaward.se/) includes user feedback processes as one of the five categories of criteria that are taken into account. We believe user feedback to be essential to the development of useful e-services, and believe that paying heed to unintended uses – the drift in the inscription – has considerable potential value (cf. [Ciborra, 2000]).

2.3.2. Legitimate imaginators, inscriptions, anti-imaginators

Any developing network exists in a world of already established networks. For someone attempting to develop support and use of a new health informatics service, this raises important questions. Who are the legitimate imaginators, who envision the manner in which the service should be used? What are their inscriptions and how strong do they appear to be? Are there counter-imaginators?

With regards to physician networks, there is probably a knowledge development network that is – at least in part – different to and separated from the “treatment

network" in which most of the daily activities take place. Many physician colleagues in the workplace, but probably not all, can be expected to form parts of the knowledge development network recognised by a physician. In addition, journals, books, and Internet resources are likely to play a part in such a network. Test labs, nurses and patients provide important input into this network, but are probably not viewed as independent actors and active parties in the network. In the treatment network, however, few other physicians are likely to appear, whereas nurses, assistants, secretaries, test labs, the (electronic) medical records, and patients are probably viewed as actors. Different physicians probably have different views regarding what constitutes the relevant networks, and other role-holders, such as nurses, secretaries, etc, can be expected to hold perceptions of relevant networks that differ from those of the physicians.

A patient's view of the relevant healthcare system probably encompasses a subsection of the treatment network recognised by the physician. In addition, there are probably actors who do not belong to the professional's view of the treatment network, such as some of the fellow patients in the waiting room, friends and family, medical literature, websites and nurse-on-telephone that the patient has consulted prior to, and after, the actual appointment with the physician. It is not obvious that these actors are visible to the physician.

Looking at a new e-service in relation to these existing networks, it is likely that the new e-service is not viewed as very important to any of the actors. In this respect, there is a sharp contrast when comparing with the imaginator and the project group trying to develop and promote the e-service, (cf. [Westelius, 1996]). To them, the e-service occupies their day and is of paramount importance. It can then be difficult for them to realise the relative insignificance of the e-service to others, and the threshold that it must pass in order to be recognised, noted, and enter the focus of attention of the patients or physicians. There is also a marked risk that promoting an innovation, that appears peripheral to the existing networks perceived by the actors, can provoke anti-programs, such as deliberate use striving to minimise the value of the innovation, or the spreading of discontent and fears that the innovation will become a prominent nuisance.

To sum up: whether or not the introduction of an Internet-based service in healthcare is intended to be part of a larger change program, it risks upsetting established power balances. The project manager can choose to side with one party or the other, but can also unwittingly adopt either a disciplinarian or supportive stance towards different users. The success of the e-service will depend on how it matches existing actor networks, and how its imaginator and proponents succeed in enrolling new actors to the network forming around the innovation. In the forming of this new network, the imaginator can attempt to retain the initial inscription of the innovation as intact as possible, or more actively support the divergent translations made by new actors.

Based on this frame of reference, we explore the processes for achieving a match between the public's needs and expectations in two Swedish ventures designed and developed to provide residents with Internet-based information and communication opportunities.

3. Data Collection

The Vårdguiden case is based on semi-structured individual and group interviews with physicians and administrators at five pilot installations. Follow-up interviews by telephone were conducted with physicians and nurses at pilot sites and reference sites using other applications for web-enabled contact between residents and physicians. The sites and interviewees were selected to provide a range of large and smaller sites, more and less enthusiastic physicians and administrators, more and less urban and more and less affluent areas. In the central project organisation, we have held a number of interviews and discussions with the project manager and the system specification manager, plus an interview with the implementation manager and one with the training manager, thus covering most of the central project management. In addition, we have studied the e-services by using the application, and have had access to the use statistics, describing the progress of the requests from the public in the administrative communication module at an aggregate level. We have not had access to the statistics regarding the website in terms of hits per page or transition paths through the website. The main part of the study was performed in 2003, with follow-up contacts in 2004.

The material for the Swedish Cancer Society case has been obtained through semi-structured interviews, documents and website use statistics. The first author has interviewed the managing director, the website and campaign manager, the web editor and the webmaster, the IT and HR manager, and three nurses operating the telephone support. We have also studied the website, related printed material, and have had access to some statistics describing the use and access patterns of visitors to the website. The study was performed during the spring of 2003 with follow-up contacts in 2004.

4. Two Swedish Health Informatics Ventures

In this section, we present two Swedish health informatics ventures, one from the non-profit organisation the Swedish Cancer Society, and the other from the public sector, the Stockholm County Council's Vårdguiden.

4.1. Vårdguiden

Vårdguiden is a Stockholm County Council venture which aims to provide County inhabitants both service and information regarding healthcare. The Stockholm County Council employs around 40 000 people in primary healthcare and hospitals. It spends around € 4 000 million per year on healthcare, or about € 2 000 per Stockholm County resident. Each year, half of the inhabitants are in contact with primary healthcare. Stockholm County has 1.9 million inhabitants in 26 municipalities of varying size. The municipalities range from the City of Stockholm itself to rural, sparsely-populated municipalities (Stockholm County Council website).

Vårdguiden consists of a printed, quarterly magazine that is distributed to all households, a telephone service, and a website. The website provides information and advice regarding how to contact primary care units and hospitals, it provides basic information for common symptoms, and contains links to other web-based health-related information sources. It is also possible to obtain assistance with reference to using Vårdguiden by means of a chat function, and to submit health-related questions in writing to an online helpdesk manned by nurses. Answers to questions can be

expected within two hours. The telephone service provides assistance in using Vårdguiden and medical advice given by nurses. All this is similar to that provided by NHS in Great Britain, through NHS Direct and NHS Direct Online, at the time of our enquiry. However, answers to e-messages could only be expected within five days; the NHS medical advice service concentrated on online self-service.

Online interaction with health clinics, for example to obtain appointments or prescription renewals, is an additional feature in Vårdguiden, not provided, at that time, by NHS Direct Online, but offered by individual health clinics within Stockholm County, by some other county councils in Sweden and by, for example, the Palo Alto Medical Foundation in the USA. Those responsible for the Vårdguiden project prided themselves on the level of security available through the Vårdguiden communication solution – privacy and authenticity were guaranteed to a far greater extent than in other known solutions. Some of the other solutions employed ordinary e-mail, a form of communication that has very low security regarding privacy and authenticity.

The Stockholm County Council reports that knowledge among the public regarding how to access the health service provided by the County Council has increased since the Vårdguiden venture was started, and by 2005, Vårdguiden had gone from being a project to being a key element in the contact between public health care and the public (http://www.sll.se).

4.1.1. Intended and unintended use

What are the networks and the inscriptions that support or hinder the use of Vårdguiden, and how do these networks view modifications of the application?

The initiator of the case management system project in Vårdguiden for communication between residents and physicians was himself a physician, who had prior experience of case management pilot systems for healthcare and who became the design and system specification manager for the project. He formed the core network together with the project manager, the technical project manager and the reference group of practising physicians. These were physicians who were interested in the internet communication idea, either because they had started pilot projects at their own clinics, or because they had participated in development councils. Within this core group, there were certainly differences of opinion, but they managed to agree upon a simple, standardised, form-based dialogue, with top security regarding authenticity and privacy. It also contained as few details as possible and limited message size in order to increase efficient communication within a few, predetermined types of cases, such as requests for appointments and requests for prescription renewals.

The dialogue options open to the physician forms one type of inscription in the case management module. A physician receiving a message is required to click either the “yes” or the “no” box in order to be able to send an answer. This design choice was formed by the reference group of physicians and the design manager of the project. It could be seen as a strong signal to the user that this is a tool geared at the efficient handling of requests. A request should either be approved or declined.

But what if the request is incomplete? The forced choice between yes and no appears to indicate that an incomplete request should receive a “No” and it is indeed used in this manner by some physicians. Others, however, would like to continue the dialogue and may wish to explain to the person posing the request where it should be sent instead. To initiate such an answer with a “No” seems rather impolite and very

formal. Another, and common, case is that the request contains insufficient information to form a decision. A request for an appointment could, for example, be so unspecific regarding symptoms that the physician is unable to determine how to prioritise the request. To initiate a request for further information with a "No" definitely feels awkward. Some physicians judge an incomplete request as a failed request, and merely respond "no". Others reluctantly check the "No" box and then write an answer, requesting more specific information with regards to the symptoms in order to further process the request. Yet others pick up the telephone and call the person having made the request, thus breaking with the case management inscription, as they feel obligated to meet the expectations of the person who has attempted to submit a request.

Those users, in these unclear cases, responding with a simple "No", are not prescribing to the pro-application network. Neither do they tend to voice their experiences regarding the shortcomings of the communication support in the form of a change request. They have seen numerous attempts to introduce inventions from central healthcare departments into their daily work, and most of these attempts fail and disappear if you pay little attention to them. If this new invention does not seem to be a tool that facilitates their daily work practices, they do not intend to spend time and effort on it.

Other users see some potential in the tool, and decide to use it in communication with those patients where they judge that the electronic contact will be useful. They select, on an individual basis, which patients to educate and which to discourage.

Yet others – and from our experience those who formed part of the initial network and took the initiative to become part of the pilot program – feel an obligation to the idea and to the network. They attempt to promote the use of the tool, try to "educate" residents, and attempt to voice their views regarding what they think should be amended in the tool.

4.1.2. Physicians' views of the e-services

The tool was released with no work processes attached. The education was geared towards introducing the program as such – with the user role types, the support organisation, and the case management logic built into the program. The education neither discussed case management norms, nor the connection between the case management module and the (large) information portal, of which the communication module formed only a part for a visiting resident. None of the physicians interviewed at the pilot sites have more than a superficial knowledge regarding the medical information website Vårdguiden, or have made any attempt to use it or suggest it in their communication with patients. The case management module has been viewed as a separate venture – and typically one with little obvious benefits. The possibility for residents being able to send e-mail requests is viewed, at best, as a convenient means of dealing with a few standard types of requests and, at worst, as an unnecessary and, for the physician, cumbersome means of serving those patients who are already well able to obtain services from the healthcare system.

Reactions to the case management module communication with patients include:

- Receiving requests by "e-mail" fills an already full day even further. It means working more (unpaid) overtime.

- The “e-mail” requests are equivalent to extra telephone hours, thereby shifting the prioritisation among work tasks in a way over which I, the physician, do not have control.
- The text-based electronic communication is cumbersome to me, but convenient to the residents.
- This is something we have to offer nowadays – e-mail communication is a standard mode of communication.
- The text-based electronic communication is a useless, but luckily very little used, means of contact for residents.
- The whole venture is an IT fad – a “sink” for funds that could have been better used.
- It is convenient and efficient for some tasks, inefficient for other.
- It is a first step towards a more integrated e-communication environment. The utility will appear if and when more systems are linked to the case management system.

As can be seen, views range from positive to rather negative. It is also noticeable that so far, there appears to have been no deliberate discussion at the clinics regarding the role the new tool will play, norms for its use, or ideas concerning how to accommodate increased use. So far, use of the system has been moderate, far lower than envisaged by the project imaginators, and also far lower than feared by some physicians. The physicians receiving most requests via the case management system, amongst those involved, have had a maximum of five per day. This amounts to between 15% and 20% of the current inflow of requests (the others typically coming during the telephone hours and, to a minor extent, by letter or as messages passed on by the reception or nurses). The normal rate, even for those physicians promoting the application actively, runs at one or two requests per day, and for those not encouraging their patients, is much lower or even nonexistent.

There is no general agreement regarding what type of case is most appropriately handled via the case management module, but prescription renewal comes high on the list. Information from the patient is often sufficient, and the case management features ensure that the request is not lost during the process – which sometimes happens otherwise. Interestingly, some physicians claim one of the most useful uses is one not originally intended by the designers. Receiving a written message is much more efficient from the physician’s point of view than receiving a call when a patient merely wishes to acknowledge that everything is OK, that the medication appears to work, or to say thank you. However, other physicians view the social contact as an important part of their practice, and are less enthusiastic about written communication, while yet others feel that they do not want to encourage feedback that they have not asked for, especially when the system in its present form requires a yes or no response to the message in order to close the case.

The most common view among the physicians regarding the incoming requests is that a more structured form is necessary. A general text asking the patient to be specific is of little use. A more detailed form is believed to guide the user to being more specific regarding points that are important for the evaluation of the request.

4.1.3. Application development and user feedback

Initially, the attitude of the central project group was that the application had been designed according to the reference group specifications, and the task at hand was to promote its intended use. Views would always exist with regards to the development of special features and extra dialogues, etc. However, the important responsibility of project management in a project such as this was felt to be standardisation, and the reaching of agreements with regards to simple and generally applicable standard dialogues. Customisation should be avoided, as it complicates the technical solution and increases the costs involved, potentially dramatically. At a later stage, the central project group planned for a gathering of physician users and a survey for the residents after a substantial level of use had been achieved, but adoption proved to be slower than originally envisioned. The gathering of physicians was intended to give them an opportunity to initiate the formation of networks around the application and to start discussing norms of use and requirements for further development. The survey investigating resident views was intended to test their appreciation of the present application, and to discover whether there were strongly felt requirements not being met by the present application. Thus no attempt had been made by the project group to design any continuous feedback systems to identify the intended and unintended use of the system and for ideas regarding its further development. However, some of the feedback received during the course of the project has led to some further development of the application.

It should be noted that the situation in healthcare is somewhat special. The central project staff has not dared design the system in order to obtain access regarding the use at each clinic. One reason was the fear of being viewed as "controllers", judging the efficiency of the particular clinic, and thereby generating resistance towards the case management module. Another reason involves the potential sensitivity of patient information. Residents using the system should be able to expect that only their physician will read their messages. The situation is thus rather more sensitive than in many other IS-related ventures, and monitoring actual traffic in the system is not without its controversies regarding obtaining feedback.

4.2. The Swedish Cancer Society

The Swedish Cancer Society is a non-profit organisation whose task it is to collect money and distribute it for cancer research, provide information concerning cancer and lending/giving support to activities which contribute, in a variety of ways, to improvements within cancer treatment and care. It has less than 40 employees and finances about ¾ of Swedish cancer research, approximately € 35 million in 2004. In addition, roughly € 5 million is spent on information and prevention. The Swedish Cancer Society is thus clearly a part of the healthcare sector, but unlike the Stockholm County Council, it is not a traditional healthcare provider.

The Society operates a central website and specific campaign websites, a telephone service, produces magazines, leaflets and other printed material, and conducts specific campaigns and events aimed at raising people's awareness and knowledge of cancer, cancer prevention and cancer treatment. In addition it also raises funds. The website contains information regarding different types of cancers, investigations, treatments, living with cancer, etc; discussion forums; information for professionals seeking grants; information for donors and members, and online donations; information for journalists, pictures, a webshop for printed material, etc;

and links to other cancer-related organisations. The telephone service, manned by nurses, provides information and the opportunity to talk about ones condition and concerns. The web also provides an e-mail interface to the nurses manning the telephone service.

The website has, for the past four years, been an integral part of the entire organisational strategy. After reaching the conclusion that the www is a strategically important communication channel that suits the Society well, every development project and campaign has had its eye on the role the website could play, and the development groups always include people, both internal and external, who are knowledgeable concerning web-based communication and website technology. There is evidence that the web-campaigns receive attention from the public. Sweden has nine million inhabitants. The Swedish Cancer Society's Quit-Smoking campaign site had 1 million visitors during its first year – the same number as the Society's central website in a year – while the "men and cancer" site had 170.000 visitors. All managers deem the www to be important to the Society, but the effect of the use of the www is judged to be greater by those who are the most involved in designing the web campaigns.

4.2.1. The telephone service

The telephone service is manned by nurses with long experience of cancer treatment. As the name "information and support line" indicates, it is not only an information service as many of the callers want someone to talk with concerning their condition and worries. It opened 10 years ago. Occasionally someone wrote a letter instead of calling. During these past few years, the telephone service nurses have also accepted e-mail – and today an e-mail function is included on the website. The number of calls has remained somewhat constant at about 6.000 per year, while the e-mails have doubled every year up to 2003. At present, written communication is approximately the same as the level of telephone contacts. E-mails are answered when the telephones are silent. The norm is to give a reply within two working days, but typically the cycle time is one day and sometimes mailing turns into an almost interactive discussion with a quick succession of e-mail exchanges.

Initially, the telephone service formed part of the Healthcare development department, working with professionals in the healthcare sector, but gradually it extended its brief into answering calls from the general public. Four years ago, the telephone service was transferred to the Information department, and has since played a prominent part in the business development and campaign planning. The nurses in the telephone service are virtually the only healthcare professionals in the Information department, and are also those who have direct contact with the public, and hear what occupies people's minds.

4.2.2. Campaigns, and mobilising the public

As in Great Britain, men in Sweden seem to know more about breast cancer than of prostate and testicular cancer. In 2003, the Swedish Cancer Society started to target younger men, using a combination of information folders, a website and advertisements – in newspapers and magazines, on billboards and on the web. Men have been a minority of those calling the telephone service and e-mailing questions. The website is believed to suit a male target group well, and the site is not only interactive but also invites communication with others. The visitor can order a reminder to perform self-examinations – an email is sent on the first Monday of each

month. There are also a number of designed, humoristic greeting cards to send to a friend, along with a greeting, to encourage the friend to perform their own self-examination. This campaign has proved to be successful, and a large number of greeting cards have been sent by visitors to others, thus leveraging the reach of the campaign.

Other examples of tapping and leveraging the potential of "residents" helping each other include a stop-smoking discussion forum and a support service for relatives. The much used stop-smoking discussion forum includes online diaries where it is possible to write about your day and others can comment and encourage. This complements an online stop-smoking program that has attracted 10.000 smokers, strengthening the program by encouraging the formation of social networks around the "stop-smoking" application.

The support service for relatives is interesting because of the interaction between the telephone counselling and the web-service. The nurses operating the telephone counselling noted that relatives of people with cancer appeared to be a forgotten group, but who had a strong need to find someone with whom they could discuss their situation. The Swedish Cancer Society then initiated a service on their web where it is possible to register willingness to act as a speaking partner – "conversation friend" – to someone who needs it, and where you can submit a request to a registered conversation friend to contact you. The web-service only deals with connecting those who want someone to talk to and those who are willing to act as conversation friends. It is then up to them to decide how they want to communicate, and that communication then occurs with no further connection to the website. In a matter of months, the Society had mustered over 300 conversation friends – a resource unparalleled by the entire Swedish public health service.

4.2.3. Capturing and using feedback from the public

Starting in April 2002, the Swedish Cancer Society has made rather ambitious use of the website use statistics. Graphical reports in the form of visitor flow tree diagrams can be studied in order to determine how users navigate through the website. These flow diagrams are discussed at monthly meetings, in a group with representatives from all the different functions within the Society, to decide whether or not the present pattern matches the original intentions. Do the website visitors find the information we are attempting to promote? Where do we lose them? Do they seem to show interest in what we believed would be interesting? To what extent do we want to encourage unexpected patterns and to what extent do we want to redesign the website (and matching parts of our ventures) to reach the effects we were hoping to reach? The use of the flow statistics is still at the developmental stages, and the understanding of the development group is still evolving with regards to the interpretation of the statistics. However, the analysis and discussion of the information with regards to use provided by the flow diagrams has already led to a number of changes in the website and has affected the design of their campaigns.

Of course, not all unintended use is welcomed. Some unexpected use is monitored and thwarted by employees (aided by private individuals with a strong feeling for a specific forum). For example, discussion postings that would compromise the reputation of the Society are removed, as are offers to serve as a conversation friend, if the "friend" serves in a professional capacity, charging for his or her services. In the telephone service, questions and requests that the nurses do not view as part of the present offer are declined or redirected to more appropriate

recipients. However, the nurses do keep track of the types of requests they receive, and topics discussed, and bring up ideas about new services or areas hitherto neglected by the Society with other members of the Information department. As described above, the nurses operating the telephone support line have, at least during the past four years, been viewed as absolutely central to the development of projects. It is the nurses who have firsthand contact with the public, and who meet their concerns, worries and expressed interest (and unexpected absence of certain concerns and reactions).

5. Discussion

Are we taking full advantage of the creative user input? Probably not, but the two ventures examined in this article provide material in order to explore the issue. The approaches noted differ between the two cases, as do the organisations and the applications. In Vårdguiden, the application is intended to support a large, distributed, and to some extent outsourced healthcare organisation. The pilot installations alone affect more physicians than the total number of employees in the Swedish Cancer Society. The focus is to create a standardised service containing the bare minimum of jointly required functionality within its interactive section. The Swedish Cancer Society raises funds for cancer research and informs the public about cancer. It provides no treatment. The Stockholm County Council, on the other hand, is primarily a traditional healthcare organisation (primary and hospital healthcare accounting for over 80% of total County Council costs).

Rather than making a strict comparison between the two cases, the differences between them should be noted. However it should still be possible to utilise both of them to further our understanding of feedback possibilities.

5.1. Integration, status and organisational size

The Swedish Cancer Society displays far greater integration between the different parts of the organisation dealing with the public than does the Vårdguiden venture. Perhaps the Society is small enough to cope with constant integration. An organisation with 40 employees differs greatly from one with 40.000. But the applications studied are also in differing stages of development. In the Swedish Cancer Society, the website and the telephone support have been regarded as of strategic importance for several years. Vårdguiden, on the other hand, is developing from a less prominent position, and the different parts were initially not even under joint leadership. This central position within the Stockholm County Council only occurred after a couple of years. In 2005, it appeared as the central portal for health-related information in the Stockholm County Council web, replacing parts that had been developed by other groups within the organisation. One interpretation is that the Stockholm County Council management viewed the Vårdguiden project as an insurance project, part of an insurance portfolio. It seemed worth attempting, even though the future of the venture was uncertain. Now, when similar healthcare portals have become more common in other public organisations, and Vårdguiden appears to work, it has been moved from an “insurance” status to a permanent production status (cf the discussion of different types of attitudes to projects in [Westelius, 2001]). The history of medical informatics is full of interesting, visionary and potentially revolutionary projects that were either never implemented or did not pass the pilot

stage. In this sense, Vårdguiden is interesting, because it is a venture that has passed the pilot stage, and achieved a central position, at least in the County Council rhetoric.

5.2. Strengthening networks around an application by linking

The Vårdguiden champions in the project management group have managed to enlist politicians to adopt their idea, at least to the extent that the technical project has been funded and the application has been rolled out to the clinics. But in order to remain central, it is expected that a health informatics venture aimed at the general public must satisfy residents' expectations and physicians' acceptance. The present Vårdguiden case management module is too small and insignificant to become widely spread and used on its own merits, given the present low appreciation from physicians and the general public. In line with the 24-hour civil service rhetoric now popular in Sweden, promoting the idea of constant and convenient citizen access to governmental agencies and services, residents in Stockholm are likely to also expect increased Internet accessibility from the healthcare sector. If they manifest this expectation clearly, then politicians will probably increase pressure to counteract physician resistance. So far, the County Council has demanded that all primary care units in one of the County's regions should be connected to the e-service portal. However, they have not yet stipulated that the e-services should be actively promoted by the primary care units or physicians. If the situation is looked at from an Actor-Network Theory perspective, pressure is probably not sufficient to achieve widespread use, cf. [Latour, 1996a; Law, 2003]. A more promising avenue would be to link the case management module, and the process of getting it accepted, with other networks [Latour, 1996b]. Integrating it with other IT systems that are more important is one means of providing the Vårdguiden network with supporting actors. Linking it with a discussion of work practices, quality norms and process improvement (the classical ground of case management systems) is another. Another important part in an enrolment program is to match the IT system with the incentive system, as argued by Petri [2001] and Monteiro [2000]. Currently that match is poor. However, if the application is viewed as important by those who control the incentive systems, the chances are that the incentive system could be modified, if required.

In the Swedish Cancer Society case, there are examples of strengthening an application by linking it to existing social networks or by encouraging the formation of new social networks. The "men and cancer" greeting cards strengthened the development of the actor-network around the "men and cancer" site by tying it to strong existing networks, namely, those formed by friendship relationships of site visitors who appreciated the site and decided to help spread its message. The quit-smoking discussion forum and chat rooms encourage the development of social relationships around the quit-smoking application. Inside the organisation, making the discussion of web statistics part of the monthly business review and development meetings was also a means of linking it to existing networks, thereby strengthening the web venture actor network.

5.3. Disciplining users or viewing unexpected use as user feedback

The typical reaction to any unintended use of Vårdguiden by residents has been to attempt to strengthen the inscription – by disciplining users, stating more clearly on the screen what the intended use is. Unintended use by residents was only viewed as

legitimate user feedback when it was also endorsed by physicians and generated explicit requests from them for modifications to the application. In the Swedish Cancer Society, there was a stronger inclination to view unexpected use as user feedback, indicating needs for modification or new services. At a meta-level, it is interesting to note how the Swedish Cancer Society firstly allowed the telephone service to move towards the general public, from an initial focus on healthcare professionals, and then, moved it to the Information department, which turned it into a central channel for impulses from the public. Looking at specific cases, the most obvious example is the telephone nurses' observation of callers' concerns regarding relatives, and the absence of support for relatives of cancer victims. This signal was picked up and led to the "conversation friend" initiative on the website. The "men and cancer" campaign was affected by the observation that men were less frequent users of the telephone and e-mail service.

The use of website visit-path statistics to "tune" the website and related activities in campaigns is yet another example of attempting to capture and make sense of unexpected – and expected – user reactions. Active use of website use statistics to evaluate the current web venture has long been advocated, but there are few published examples of actual practice, and many comments about the difficulty of making sense of "click-stream data". The Swedish Cancer Society example appears to indicate that it is possible to make useful interpretations in a healthcare setting.

6. Conclusions

Summing up, there is evidence in both the literature and our case studies that a gap exists between what is technically possible and what is actually implemented and used. Increased use of the www and the Internet can be expected to be appreciated by at least a section of the public, and possibly also increase the quality of such healthcare where patients play a prominent role. However, the potential controversy noted in the literature, that these advantages will be accompanied by problems and costs for physicians and healthcare institutions, was also upheld to some extent by our Vårdguiden case. On the other hand, the Cancerfonden case mostly provided examples of beneficial uses, but probably with a greater potential than currently exploited.

Whether or not the introduction of an Internet-based service in healthcare is intended to be part of a larger change program, it risks upsetting established power balances within healthcare organisations or between healthcare providers and patients. The project manager can choose to side with one party or the other, but can also unwittingly adopt a disciplining or supportive stance towards different users. As Actor-Network Theory proposes, the success of the e-service will depend on how it matches existing actor networks, and on how its imaginator and proponents succeed in enrolling new actors to the network forming around the innovation. In the forming of this new network, the imaginator can attempt to retain the initial inscription of the innovation as intact as possible, or more actively try to support the divergent translations made by new actors. The Vårdguiden project management tried to provide residents with e-services, but without upsetting physicians, whose cooperation is vital to the venture. Initially, the project management attitude towards unintended use was to view it as errors to be corrected. The response was then to reinforce training and information. As some physicians have also come to support some unintended use, these uses have been viewed as user feedback, leading to

modifications of the system. In the Swedish Cancer Society case, unintended use has for a number of years been viewed as important feedback signals suggesting needs not being met. In some cases it has led the Society to launch new services or campaigns. In other cases, the society has encouraged the formation of networks that support or cater to the needs thus identified.

We noted that a new e-service faces a number of established networks, and that the imaginator behind the e-service is likely to overrate the significance of the new e-service to its intended users. In the Vårdguiden case, the use of the e-services has been far lower, and has been growing at a slower rate, than envisaged by the imaginator. In the Swedish Cancer Society case, the gap between potential and actual use appears to be much smaller. We conclude that an attitude towards unintended use as a source of further valuable adoption and use of the application, and the identification and promotion of networks that support the use of the e-service are two important factors involved in closing the gap.

Acknowledgements

The research has been funded by a research grant from VINNOVA, the Swedish Agency for Innovation Systems.

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