Patient-Based Mobile Alerting Systems – Requirements and Expectations

Doris Jung & Annika Hinze

University of Waikato, Department of Computer Science
Private Bag 3105, Hamilton, New Zealand
{d.jung, a.hinze}@cs.waikato.ac.nz

Abstract

Patients with chronic conditions are not well supported by technical systems in managing their conditions. However, such systems could help patients to self-reliantly comply with their treatment. This help could be rendered in the form of alerting patients about condition-relevant issues, transmitting relevant parameters to healthcare providers and analysing these parameters according to guidelines specified by both patients and healthcare staff. If necessary, this analysis of condition parameters triggers the alerting of patients and healthcare providers about actions to be taken.

In this paper, we present the results of a survey we have undertaken to verify and extend requirements we have identified for the design of a Mobile Alerting System for patients with chronic conditions. First of all, the results show that a Mobile Alerting System is desired by patients. Moreover, due to the inter- and intra-user variance of patients and healthcare staff, the system has to work in a context-aware manner and allow for personalised parameters in order to be adaptable to every user's needs.

1. Introduction

In health informatics patients with chronic conditions are often neglected in the support of the management of their diseases. There are various systems that support clinical staff in the management of their workflow but hardly any systems that take the required all-embracing approach in directly supporting patients themselves in the management of their own treatment: Patients should be able to independently define reminders of condition-relevant issues and actively monitor their own health to improve the results of their treatment.

In our prior work [1] we found that a system suitable for this kind of patient support needs to be a mobile system that is able to alert patients of condition-relevant issues. In [1] we have suggested such a system helping patients to master the organisation of their medication regime and doctor appointments, to lead a healthy lifestyle and to keep condition-relevant parameters under control. Initially, we undertook a first-cut requirements analysis for the determination of the requirements for the Alerting System. This analysis was based on a series of interviews taken in a university clinic, on the basis of posts on condition-relevant newsgroups that were actively followed and on several use-case developments. In order to verify and extend the requirements found in this first-cut analysis, we have conducted an online survey, the results of which we will report in this paper. The form of an online survey was chosen since we wanted to reach potential users of a Mobile Alerting System. We assume that only people who are computer-literate enough to participate in an online survey would be candidates for using such a technical system.

To the best of our knowledge, this survey is the first of its kind focused on the demands of patients for alerting, their desired subjects and uses for this kind of information delivery as well as their preferences for alerting modes. Though there have been several studies that analysed related approaches, none of them dealt with patient-based Alerting Systems. The focus of [2] was to analyse the impact of electronic systems on the compliance of patients. Preferences for the modes of alerting have been investigated in [3]. The evaluation in [4] investigated the improvement of the response to laboratory results due to alerting. The aim of [5] was to analyse the usability of a clinical Alerting System. The works in [3, 4, 5] focus on the evaluation of several aspects of Alerting Systems. However, these studies only target clinical staff. Evaluations of patient-based approaches such as [2] miss the analysis of alerting components due to the lack of such technology in current systems.

The remainder of this paper is structured as follows: In Section 2 we describe the methods used for our survey. Afterwards, in Section 3 we present the results both of the quantitative (Section 3.1) and the qualitative part (Section 3.2) of our survey and their evaluation. To conclude, we discuss the results of the survey and outline our plans for future work in Section 4.

2. Methods of the Survey

As described in the introduction, we have found several requirements for a patient-centred Mobile Alerting System in a first-cut requirements analysis, the results of which we present in [1]. With the intention of verifying and extending these requirements we have undertaken an online survey during the two last weeks of February 2005. The survey was directed towards patients, doctors, nurses as well as computer scientists employed at IT departments of clinics.

For our survey we have chosen a mixed approach since we had two objectives in mind. On the one hand, we needed to verify those requirements we had already found, on the other hand, it was important to explore the topic more thoroughly and to identify requirements we ourselves had not yet thought of. Hence, we used quantitative methods complemented by a number of qualitative questions. For this mixed approach, we chose the concurrent nested strategy as suggested in [6]. The quantitative method was guiding the survey to promote the participants' understanding of the issues involved before actually starting to ask any qualitative questions. The evaluation of the quantitative questions we approached based on grounded theory [7].

2.1. Participants

In our online survey a total of 73 questionnaires were filled in by the participants during the time of the study. Three of them were obvious outliers which we removed from the result set. Two of them were identified as outliers because they were duplicates of 2 other results, i.e. the participants have accidentally submitted their questionnaires twice. The third outlier was due to a spammer, who announced having submitted this faked questionnaire.

Status

Sixty of the remaining 70 participants were patients, with several of them also indicating a second status. The distribution of these statuses is given in Figure 1. About half of the patients had no other status; 13 were computer scientists and therefore well versed with technical devices. There were 4 nurses, whose responses did not appear to be significantly different from those of any other patient. Among the participants who gave another status, positions were named such as dietician, biologist and family member of a patient.

The other 10 questionnaires were filled in by 1 doctor, 2 nurses and 7 computer scientists. Since the number of completed questionnaires for doctors, nurses and computer scientists is so small, we decided to analyse only the results of the patient questionnaires.
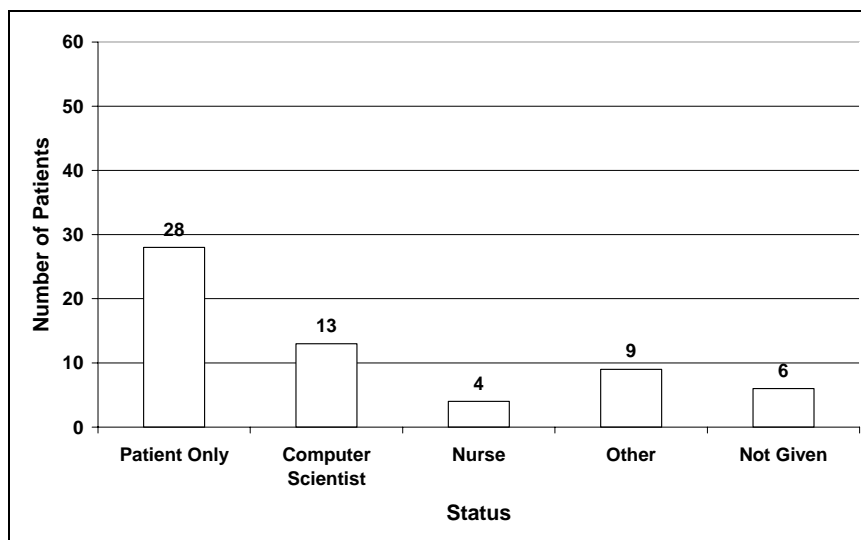

**Figure 1 – Further Statuses of Patient-Participants**

Personal Background

Thirty-five of the patients who filled in the 60 questionnaire gave their gender as male and 23 as female. Two people did not specify their gender. This may appear not representative due to the male domination. Nevertheless, in a highly computer-literate target group this distribution matches the real situation.

Our participants were between 18 and 79 years old with a mean of 40 years and a standard deviation of 15.65.

Their spread of the nationalities is depicted in Figure 2. The two major groups were Americans and Germans with the Americans constituting the bigger group. These groups were followed by Canadians and New Zealanders. Six people did not specify their nationality. This reflects the distribution of nationalities of participants in international online

communities. When observing the number of involved New Zealanders their number is higher in the survey responses than their proportion in the world population.
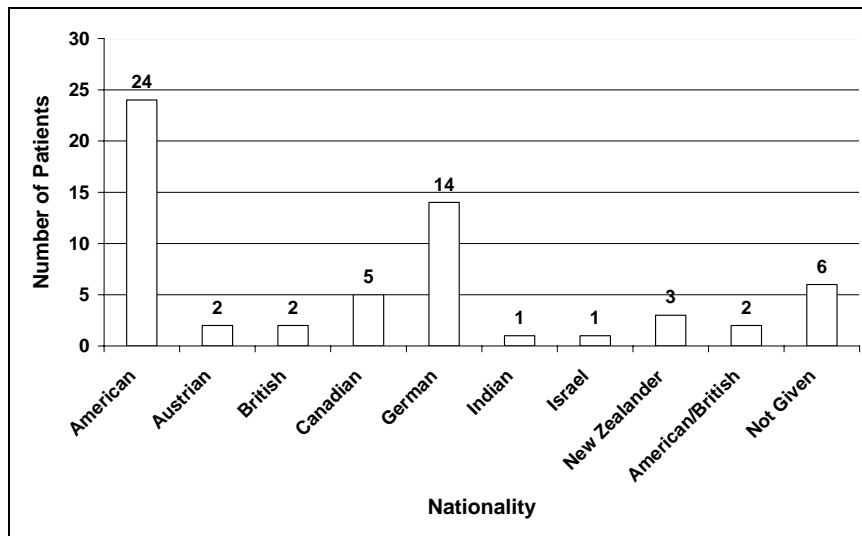
Figure 2 – Nationalities of Participants

Conditions

Among the participants we found an uneven spread of conditions, which is most likely caused by the way we approached patients. For two conditions we had patients posting our announcement to online communities. These patients were well known in communities concerning inflammatory bowel diseases (e.g. Crohn's disease and ulcerative colitis) and glaucoma, respectively. The large number of participants with diabetes is due to the posting of our announcement at a particularly active diabetes newsgroup. This group explicitly deals with diabetes research. The actual distribution of conditions is depicted in Figure 3.
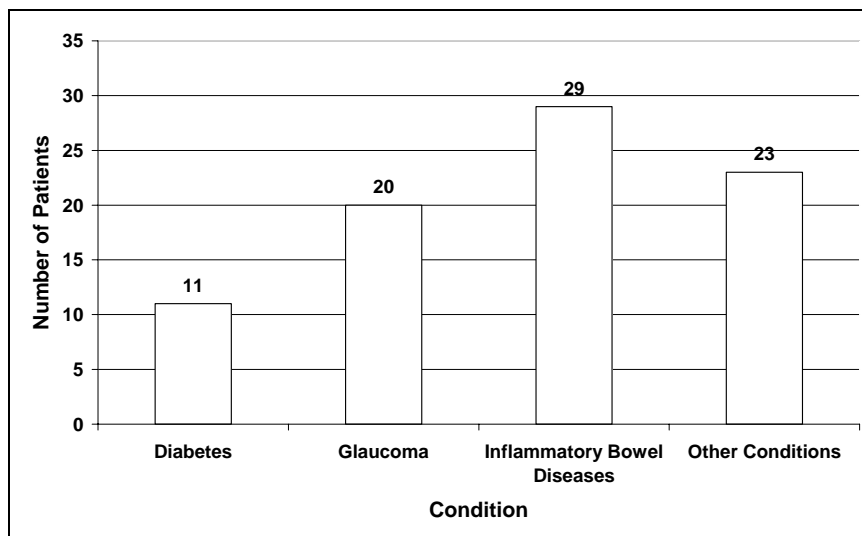
Figure 3 – Conditions of Patients

Computer-literacy

The participants of the survey all were rather computer-literate. On a scale from 1 to 5 they judged their own experience in using computers and other technical items with a mean of 4.09 and a standard deviation of 0.98.

The median of their hours of computer use was 30 hours per week. The participants have been using computers for 14 years as the median.

2.2. Procedure

After classifying the participants of our survey we now give a brief overview of the procedure we used to gain and analyse the data.

Entry into the Field

Information about our survey was posted to online communities of support groups for patients. This was done via a number of English and some German speaking mailing lists and newsgroups covering various conditions. The conditions that were addressed are diabetes, glaucoma, AIDS, hypertension, polycythaemia, leukaemia, arthritis and inflammatory bowel diseases (IBD). In order to guarantee the appropriateness of the posting to the list, for mailing lists the announcement was sent to the moderators of the lists. As a consequence, for some diseases the announcement was not forwarded to the list, e.g. for several lists supporting AIDS patients. For two conditions the announcement was posted through actual patients, who were well known to the list members by their postings to the respective lists. The conditions affected by this are IBD and glaucoma.

Additionally, several doctors, nurses and computer scientists working in clinics were contacted directly via e-mail and asked for their participation.

Data Sources and Analysis

The data for our analysis was collected by an online survey within a period of 2 weeks. The results of the questionnaires were sent to us anonymously.

We used a mixed methods approach, namely the concurrent nested strategy (cf. Cresswell [6] for details). For the quantitative analysis we followed [8]. For the analysis of the answers to the qualitative questions, we have chosen techniques following the grounded theory approach as described by Creswell [7].

3. Results of the Survey Analysis

In the following we present the results of the analysis of our survey. In Section 3.1 we discuss the quantitative results followed by a qualitative analysis in Section 3.2. Next to our evaluation in these two sections a concluding discussion can be found in Section 4.

3.1. Quantitative Results

The part of our survey asking quantitative questions presented requirements we had found in our first-cut requirements analysis to patients. Thereby we wanted the participants to give their opinion on these requirements in order to verify their validity and to determine their relevance.
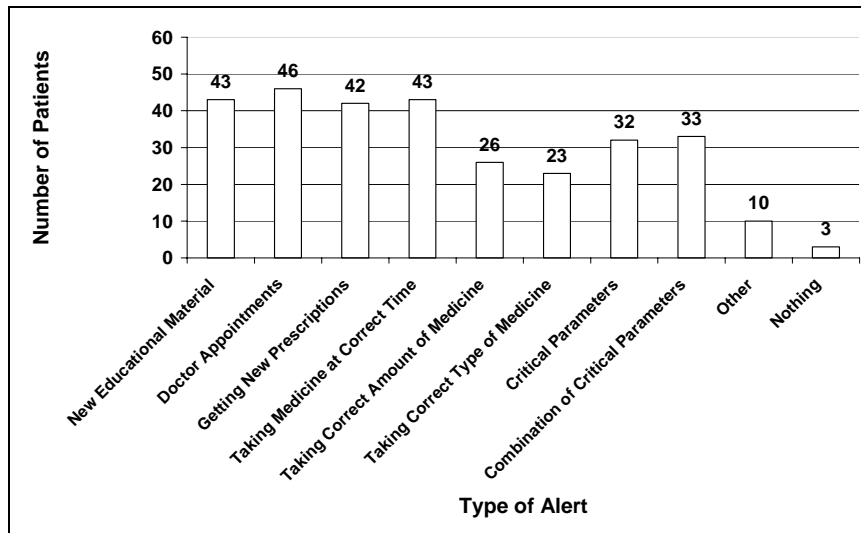
Desired Information

Concerning the question which information patients would like to be stored and available for them personally, they were very interested in storing information on their current medications and adverse effects of their medications. Furthermore, they favoured the storage of possible interactions of their medications with other medications and their parameters measured by themselves or clinical staff. However, they were indifferent about the storage of their personal data in combination with the information mentioned before. This could be due to the fact, that their personal data is something they do not need to be reminded of, it could be due to data security reasons (even though patients were asked to abstract from this when answering this question), or it could be due to the fact that the participants did not consider the need for an association between their medical and personal data in order to be used successfully for their treatment.

Types of Alerting

The question about what issues patients would like being reminded of was answered in a way which clearly showed that overall alerting is something which is desired by the participants of our survey, i.e. computer-literate patients. Only 5% were not interested in receiving alerts (cf. Figure 4). Nevertheless, these patients were still interested in a support system for the management of their condition that they could use for storing information and querying the system for it.

Figure 4 shows that more than two thirds of the participants are interested in alerts about new educational material and reminder alerts, such as being reminded of doctor appointments, getting a new prescription or to take their medicine at the correct time. Only about one third of the participants wanted to be reminded to take the correct amount of medicine, or the correct type of medicine. This can be explained by the fact that this information is not so easily forgotten: patients rather feel the need to be reminded to take their medication at all. Usually, the amount and kind of medicine will then be remembered automatically.

About half of the participants were interested in alerts concerning their health-related parameters. These personalised alerts are triggered according to definitions doctors have specified, e.g. when a patient's blood sugar values are too high or when visual fields, cup/disc ratio and eye pressure suggest the progression of damage in glaucoma.

Figure 4 – Which Alerts do Patients Want?

Alerting Signal

We evaluated in what way patients want their attention to be drawn to any new kind of information they are being alerted about. Participants could choose between audio, visual and vibration signals. Thereby, they had the option to select between "home", "night" and "business". Furthermore, the selection of the signal had to be made depending on the medical priority of the alert. As expected, for a high medical priority, patients wanted a vibration signal, if they are on business. When they are at home or during the night they prefer an audio signal to indicate a high priority alert. For a medium medical priority patients still prefer to be alerted with a vibration signal when they are on business. At home and at night they favour visual signals for medium priority alerts. This most likely stands in connection with the fact that patients do not want to be disturbed at night. For all low priority alerts visual signals were desired by the participants. The overall percentage of patients indicating a visual signal was relatively stable independently of the medical priority and the time of the day. We assume that patients have chosen visual signals, since these signals might imply the utilisation of e-mails as medium, which allows for easier documentation.

Alerting Medium

When asked in what way patients would like to receive condition-related information, the results of this question for the alerting medium showed similar tendencies for their preferences at home and at night. For all times of the day, patients favoured receiving e-mail in an equal proportion. This is most likely due to the fact that patients want to archive alerting messages. Though, they hardly ever wanted e-mail as the sole medium of alerting. This was the case only for a low medical priority. Both printouts and automatic entries into EHRs are also wished for in relatively equal proportions independently of the medical priority. So, once patients have opted for an automatic documentation of their condition they prefer to stick to this decision always. As expected, patients were less interested in voice messages when being on business. For a high medical priority the favoured alerting medium was always the text message.

Alerting Device

The question of which devices the participants would like to use to get informed about condition-related issues, patients generally favoured devices such as their home computer, the phone, a mobile phone or a mobile device (e.g. integrated into a watch). The exact distribution of devices is given in Figure 5. It was striking that when being on business patients preferred using their personal mobile phone/device and did not like using office devices provided by their employers. Our assumption is that patients do not want to give their employer the possibility to find out about or to track their condition. Another reason could be the desire for a strict separation of personal and professional life. The interest in using a home computer remained relatively stable independently of the time of the day. This is most likely due to the fact that patients would like to use their home computer to document their condition themselves. In the qualitative part of our survey this was also hinted at by the fact that a high number of patients wanted the possibility to plug in the mobile device into their home computer via USB.
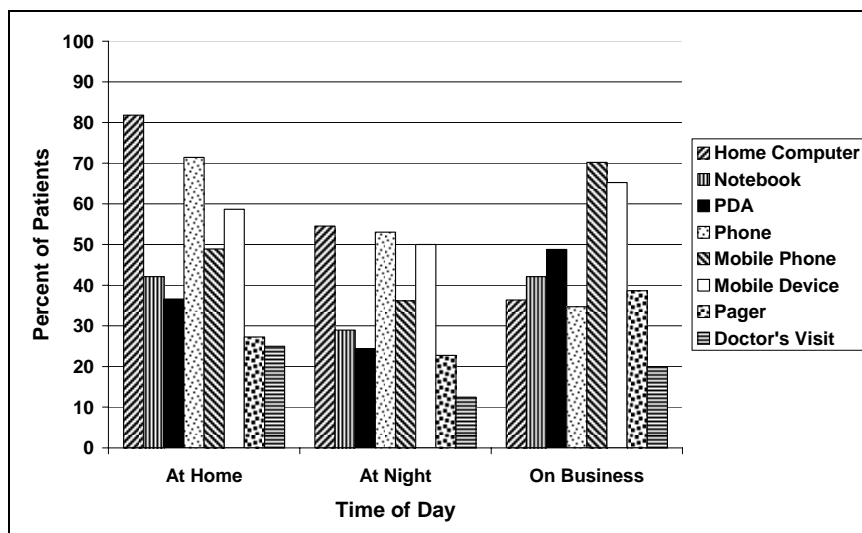
Figure 5 – Preference of Devices

Input and Output

In respect to the preferred form of output we obtained the results depicted in Figure 6. Most participants preferred a visual output in the way they are accustomed to working. However, several patients have special needs and preferred a voice feedback. Among these participants it was striking that approx. 78% either had glaucoma or diabetes. Fifty percent of all glaucoma patients, approx 36% of all diabetes patients and approx. 14% of all IBD patients wanted the possibility to use voice feedback. This clearly suggests the need for a voice feedback due to bad eyesight.

The answers to our question regarding the preference of giving input into the system were not as obviously defined by the patients' conditions as the answers for the preferred output. An overview of the answers is shown in Figure 6. The tendency which seems to emerge though is that patients with vision problems also seem to wish a voice input. However, they wish a voice input to a lesser extent than they wish to have a voice output. A voice input is also favoured by patients who have problems with movements such as patients with MS or rheumatoid arthritis. Most of the participants who wished for another input had mistaken this question for a question asking about what devices they would like to use and answered things such as palm device, website, computer or PDA.
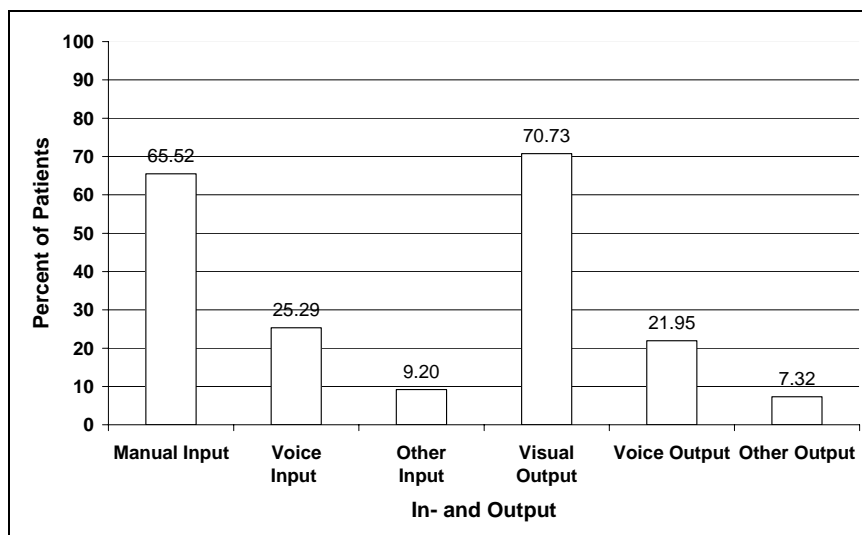

Figure 6 – In- and Output

Level of Functionalities

The question for patient needs concerning the desired level of functionality the system should offer was answered in various directions. It was possible to select several options. None of these selections was clearly favoured by patients: Almost 40% wanted to have basic functionalities and around 54% wished for advanced functionalities. Another 66% was looking for default functionalities.

Another question asked was concerning the trade-off between a basic level of functionality with an easy-to-use interface in comparison to a sophisticated level of functionality with an interface one has to learn. Here the participants opted for the exact middle. This stands in opposition to their statements in the qualitative part of our survey where they stated that they prefer an easy-to-use interface. So, further research is required for clarification.

Confidentiality

When asked for their concern about general issues of confidentiality and data security the participants were overall extremely concerned. Our participants had to tick one value on a scale from 1 to 5 for the issues of data integrity, authenticity, non-repudiation and confidentiality, respectively. These choices resulted in a median of 5 for each of the three first categories. For the matter of confidentiality the median was located at 4.

Next to the quantitative questions required for both the verification of our first-cut requirements analysis and the determination of the relevance of the particular requirements, our survey also contained qualitative questions. They are intended to extend our requirements found so far and are presented in the following section.

3.2. Qualitative Results

In the parts of our questionnaire asking qualitative questions the main areas we were inquiring about were alerting, data storage and any additional requirements patients would set into a Mobile Alerting System. This section of the questionnaire aimed at the investigation of further requirements not covered by our first-cut requirements analysis.

For the analysis of the qualitative results we have used an approach based on grounded theory [7]. This approach consists of three phases: the open coding phase (categorisation of given answers), the axial coding phase (relating categories to identified central phenomena) and the selective coding phase (building a "story" around the categories, i.e. within the background of our study the development of context and hypotheses).

During the open coding phase we started by segmenting the issues covered by our participants into single information units. Afterwards, we grouped them into 5 categories: usability, technical requirements, design (aesthetics), stored information and alerting. As central phenomena for the axial coding we could clearly identify two categories, alerting and stored information. We then elaborated the relationships between these central phenomena and discovered the influences of the remaining 3 categories on these central phenomena. Finally, in the last phase (selective coding) we encountered that our participants stated the need to store a great amount of data without specifying the way of accessing it. Since they excluded to be alerted about them, we deduced that a category "querying" was required but not explicitly specified by our participants. In the end we successfully related phenomena and categories to each other.

To allow for a better overview of the variety of answers given by patients and our deduced 5 categories we present them graphically in Figure 7. There we also visualise the interconnections of these categories to show their influences on each other.
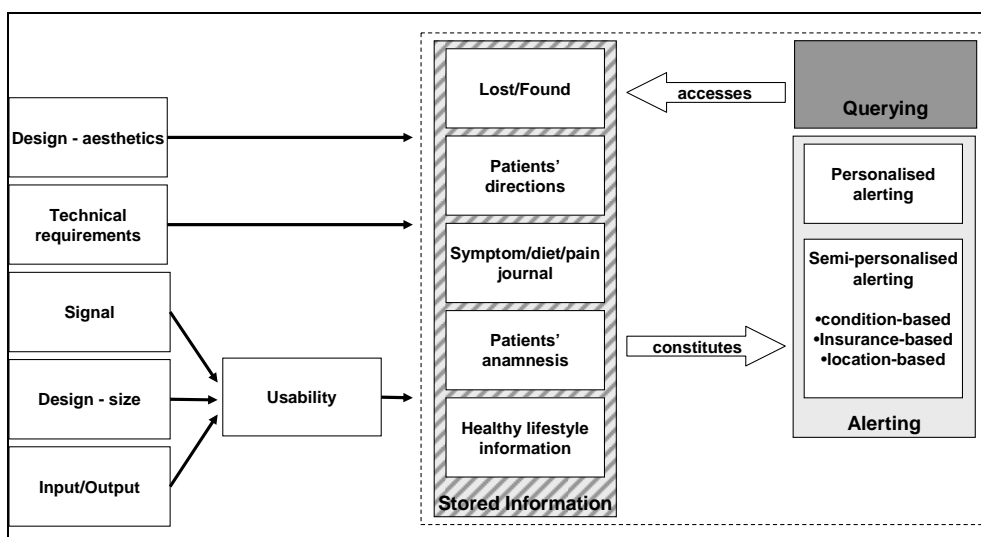
Figure 7 – Model of Relationships between Requirements and Functionalities

Out of the evaluation of the qualitative questions regarding the category alerting functions we realised that patients' needs are extremely diverse. Thus, context-dependent alerting is required to suit each patient. The context which has to be taken into account for the alerting functions covers areas such as the conditions of patients, the current location of patients, their mood, general disposition, educational background and the time of the day. To be able to realise context-dependent alerting we require a context-aware storing of personalised information. Another reason for the need of

personalised information storage is an issue which, even though not directly stated by the participants, was the inescapable conclusion of the fact that patients wanted a lot of information to be stored but not to be alerted about it. Many of the patients wanted to have an electronic journal to jot down their symptoms, dietary needs or pain patterns. Also healthy lifestyle advise and lost/found information (e.g. owner details and acoustic help to find a lost device) are rather information to query for when needed than to be alerted about. However, the mode of access (querying vs. alerting) might vary depending on a patient's condition: A patient with IBD might want to be alerted about dietary information, for glaucoma patients that is extremely unlikely and they would prefer to query the system for this kind of information.

When asking for further requirements for the Mobile Alerting System, issues mentioned repeatedly were concerns regarding the category of the usability of the system. In general, patients favoured an easy-to use system. In more detail, they were extremely concerned about the size of the device carrying the system. They all wanted a device in pocket-size. Any smaller size would yield a negative trade-off between the ability to easily take along the device and the possibility of sophisticated functionalities.

Some participants also gave comments on the signal that should be used. The participants who commented on this issue said that they would favour a vibration signal. Concerning the in- and output of the device carrying the system the participants expressed a range of positions: Some clearly wanted a visual display whilst others mentioned vision problems and would therefore prefer an audio in- and output. In opposition, others with poor eyesight still wanted a visual display but required that this should be easily readable.

Our participants also expressed some concerns regarding the category of technical requirements of such a Mobile Alerting System. There statements covered subjects such as low energy consumption, problems in cases of no reception, the ability to employ the system internationally and the possibility to connect the mobile device via USB to a home computer. A further issue which appeared to be important for some participants were the category of aesthetics of the device. Nevertheless, one participant mentioned the exact opposite, namely, that the design does not matter at all.

To summarise, in this section regarding our qualitative analysis we have developed a model of the relationships between requirements and functionalities of a patient-based Mobile Alerting System. This model has extended the requirements we had identified in our first-cut requirements analysis.

4. Conclusion and Future Work

In this paper we have presented the analysis of the results of a survey regarding the requirements of a patient-based Mobile Alerting System for the support of patients with chronic conditions. We have undertaken this survey with the intention of verifying and extending our requirements identified in a first-cut requirements analysis [1]. We chose as medium an international online survey to aim at relatively computer-literate participants, since these are potential users of our system. Compared to the worldwide target group the number of participating New Zealanders lay above the average.

We started by explaining the methods used for the design of our survey. Then, we presented an evaluation of the quantitative results of the survey followed by an analysis of the qualitative results. If we now relate the correlation of our quantitative and qualitative results to the requirements of our first-cut analysis we find that in the categories of alerting and stored information our initial requirements have been fully verified. This verification also seems to hold for the system usability. However, one aspect, the desired level of functionality, has led to slightly contradicting results in the qualitative and quantitative analysis. Thus, this topic needs to be addressed in future research. Next to these verifications, our survey resulted in extensions of our requirements regarding alerting and stored information. Our participants also stated several technical requirements and design matters we had not explicitly asked for and thereby our initial set of requirements was extended.

In particular the results of our survey evaluation are:

1. Alerting about condition-relevant issues is wanted enthusiastically by patients with chronic conditions. This was shown in both our quantitative and qualitative analysis: 95% of our participants were interested in reminders in general but their personal needs varied extremely.

2. Due to the wide spread of personal circumstances (e.g. conditions and educational background of patients) context-aware storing, alerting and querying is required. This is implied by our qualitative analysis as well as the component of the survey regarding usability in our quantitative analysis.

3. Regarding alerting functions, data querying, data storage and interface issues both personalisation (for individual patients) and semi-personalisation (for groups of patients, e.g. with the same condition) is required.

4. The usability of our proposed Mobile Alerting System is a highly relevant issue due to the special needs of patients with chronic conditions.

However, there are open problems that need to be addressed in the future. Due to the contradicting results in the qualitative and quantitative analysis regarding usability aspects, the exact needs and requirements of the broad group of patients with chronic conditions have to be both more thoroughly examined and investigated in a field study. This includes topics such as the potential varieties of audio feedback (e.g. voice feedback, acoustic signals, differentiating music). For an extension and achievement of our original aim, i.e. to gain a complete picture of requirements for a Mobile Alerting System, we are considering undertaking selected doctor interviews.

5. Acknowledgments

6. References

[1]   Jung D, Hinze A. A Mobile Alerting System for the Support of Patients with Chronic Conditions. In: *Proceedings of the First European Conference on Mobile Government (EURO mGOV) 2005*. Brighton, UK; July 10-12, 2005 (to appear).

[2]   Palermo TM, Valenzuela D, Stork PP. A Randomized Trial of Electronic Versus Paper Pain Diaries in Children: Impact on Compliance, Accuracy, and Acceptability. *Pain* 2004; 107(3):213–219.

[3]   Wagner MM, Eisenstadt SA, Hogan WR, Pankaskie MC. Preferences of Interns and Residents for E-mail, Paging, or Traditional Methods for the Delivery of Different Types of Clinical Information. In: *Proceedings of the American Medical Informatics Association (AMIA) 1998 Annual Symposium*. Lake Buena Vista, USA; 1998. p. 140–144.

[4]   Kuperman GJ, Teich JM, Tanasijevic MJ, Ma'Luf N, Rittenberg E, Jha A, et al. Improving Response to Critical Laboratory Results with Automation: Results of a Randomized Controlled Trial. *Journal of the American Medical Informatics Association* 1999; 6(6):512–522.

[5]   Zheng K, Padman R, Johnson MP, Engberg J, Diamond HH. An Adoption Study of a Clinical Reminder System in Ambulatory Care Using a Developmental Trajectory Approach. *Medinfo* 2004; p. 1115–1122.

[6]   Creswell JW. *Research Design: Qualitative, Quantitative, and Mixed Methods Approaches*. 2nd ed. Thousand Oaks: SAGE Publications, 2003.

[7]   Creswell JW. *Qualitative Inquiry and Research Design: Choosing Among Five Traditions*. Thousand Oaks: SAGE Publications, 1997.

[8]   Moore DS, McCabe GP. *Introduction to the Practice of Statistics*. New York: W. H. Freeman and Company, 2003.