An Exploratory Study of Patient Attitudes towards Symptom Reporting in a Primary Care Setting

Benefits for Medical Consultation and Syndromic Surveillance?

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Keywords
Electronic symptom reporting, physician-patient relations, consumer participation, data collection, communicable disease control

Summary
Objectives: The aim of this study was to investigate people’s attitude towards providing symptom information electronically before a consultation. Specific areas investigated include a) attitudes and experiences with regards to acquisition of information related to symptoms, b) attitudes towards computer based communication of symptoms to the general practitioner and how they preferred to carry out such reporting, and c) attitudes towards storage, use and presentation of symptom-data in general, and particularly in a symptom based surveillance setting.

Methods: Data was collected from 83 respondents by use of convenience sampling.

Results: The respondents were familiar with using the Internet for health purposes, such as acquisition of information related to their symptoms prior to a consultation. The majority of respondents had a positive attitude towards providing information about their symptoms to the general practitioner’s office as soon as possible after falling ill. Over half of the respondents preferred to use e-mail or a web-interface to perform this task. Eighty four percent were willing to have their symptom data stored in their EPR and 76 percent agreed that the general practitioner might access the symptoms together with the prevalence of matching diseases in order to assist the diagnostic process during the next consultation.

Conclusions: The results of this study support the applicability of electronically mediated pre-consultation systems both for improving primary care consultation and for use in symptom based surveillance, including real-time surveillance.

1. Introduction

In countries with high e-readiness, patients could report symptom data in real-time through information and communication technologies prior to a medical consultation. Although such services could be argued to be available to young and technology savvy segments of the population, it appears that most patients [1], including elderly or less-educated patients [2], are strongly motivated to use electronic services. Symptom-data collected in this manner could impact healthcare on at least two levels: 1) On a dyadic/individual level as a means of improving efficiency, focus and quality of the medical consultation and 2) on a population level in prevalence and incidence reporting that could be utilized in symptom based surveillance.

1.1 Electronically Reported Symptoms to Improve Doctor-patient Communication

In many cases the physician finds it challenging to determine the patient’s main problem or concern [3]. Physicians indicate that the way patients present their problems, including presentation of symptoms (e.g., indications of importance and/or severity) and the sequence of symptoms, are very influential in determining their professional interpretation [4]. Likewise, studies investigating interviewing styles in medical care show that physicians elicit only slightly more than 50 percent of the medical information considered important [5].

Seventy-one percent of the Internet users in seven European countries use the Internet for health purposes, where the main health-related activity is information seeking [6]. This health-related use of Internet affected the patients’ use of other health services, and as many as 30 % of the Internet users interact electronically with health professionals [6]. We suggest a future health related use: Pre-consultation, electronic symptom-reporting to help the patients to clarify and grade the important symptoms. This could help enhance the validity of the medical examination and reduce the diagnostic process during the next consultation.

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Methods Inf Med 2011; 50: 479–486
doi: 10.3414/ME11-02-0005
received: January 14, 2011
accepted: July 5, 2011
prepublished: September 7, 2010
and severity of their symptoms. These data could then be used by patient and physician in order to focus their conversation on the most pressing topics/symptoms, increasing both efficiency and quality of the medical consultation. For instance, patient satisfaction with a consultation appears related to both consultation length and to the medical decision made during consultation (e.g., correct diagnosis, treatment regimen) [7]. Obviously, in order to diagnose correctly and treat efficiently the physician needs the information provided by patients to be as accurate as possible.

With regards to traditional approaches to non-acute symptom reporting, where the patient typically reports symptoms retrospectively or as an average over time, the accurateness of patient reports might be in doubt. For instance, patients have increasing difficulty remembering symptom levels beyond the past several days, and the length of recall impacts the accuracy of symptom reporting [8]. A study of chronic pain patients demonstrated that end-of-day ratings of pain were highly accurate representations of average levels of pain experience across a day [9]. End-of-day ratings were better representations of momentary ratings than recall ratings [9]. Such data can be used retrospectively to indicate average symptom levels over time. Thus, systems that allow for real-time reporting of symptoms would give highly accurate single-point ratings (e.g., end-of-day), while also allowing more accurate average ratings.

An informal literature review revealed that utilization of pre-consultation electronic symptom reporting tools is not uncommon in specialist healthcare [10–13]. Studies from this context indicate that patients perceive pre-consultation reporting of symptoms and concerns to be associated with higher levels of care [10]. Also, in emergency asthma care parents’ reports have demonstrated to improve documentation for key variables that impact quality and safety [13]. In addition, such solutions could be extended to provide other information relevant to the medical consultation, for instance individual patient information needs [14].

However, little evidence exists from primary care settings. A recent pilot study investigating use of online tools in primary care found that an online-exclusive, “e-visit” system was feasible in practice and saved consultations between general practitioners (GP) and patients [15]. This supports the idea that electronic tools could help register and communicate patients’ medical history, for instance by providing higher levels of organization and structure, detection of new symptoms, and provide higher clinical performance and patient satisfaction [16, 17]. Thus, such systems appear to alleviate some of the key challenges facing both patients and medical personnel in primary care.

1.2 Electronically Reported Symptoms to Improve Syndromic Surveillance

Aside from the impact symptom registration might have on dyadic communication and related treatment processes, data collected by these means could also be used on a broader scale. Successful disease surveillance and management is relying heavily upon the quality of registered data. The importance and relevance of disease surveillance and management were emphasized through the recent swine-flu pandemic and through the fact that infectious diseases account for around 25% of all deaths in the world [18]. However, studies show that traditional disease surveillance systems are associated with a considerable reporting lag that limits early detection and timely response to outbreaks [19, 20]. Consequently, there is a demand for new electronic surveillance systems capable of eliminating unnecessary delays and reducing the risk of data corruption [20].

Methods exploiting clinical data that exist at a stage before a confirmed diagnosis (e.g., symptoms) are commonly referred to as syndromic surveillance [21] or symptom based surveillance. Typically, in syndromic surveillance the frequency of illnesses is monitored using a specified set of clinical features (e.g., fever and respiratory complaints, skin rashes, diarrhea) in a given population of a given geographic region, regardless of specific diagnoses [22]. It is the real time nature of the syndromic surveillance systems that makes them valuable for outbreak monitoring and detection [21]. Syndromic surveillance is considered useful for general public health, quality improvement, epidemiology, patient safety and research [21]. However, perhaps most important is its usefulness in clinical medicine [21], where it can make clinicians aware of community trends and enable them to issue the right tests and improve their diagnostic assessment [23].

Secondary use of clinical data, for instance structured documentation from the electronic patient record (EPR), unstructured narrative text, or laboratory results, is expected to have large potential [24]. Today the necessary technologies are available to extract and present surveillance data from EPRs, laboratories, and hospitals [25]. However, the validity of a syndromic surveillance system depends on the quality of the collected and presented data, both in terms of representativeness and completeness [26]. A key challenge in utilizing such systems and technologies is to define the optimal data sources [27]. Unfortunately, data sources such as ICPC codes, free-text fields in the EPR, and data generated in conjunction with laboratory orders and results might have serious limitations [28]. One explanation is that the data entered into the EPR by the GP is intended for other purposes than disease and/or syndromic surveillance, and produced in a different context. Information always has to be conceptualized as entangled with the context in which it was produced [29]. Consequently, for secondary use of medical data the information must be disentangled from the production context [29], and transformed into the new context of disease or syndromic surveillance. This process is particularly challenging with regards to real time data.

At the present, the challenge is to collect real time data of proper quality that is produced also for the purpose of disease or syndromic surveillance. Since patients could be seen as the GP’s primary source of information on the current prevalence of infectious diseases [30], it seems appropriate to exploit this primary source by collecting symptom information directly from the patients. In countries with high e-readiness, such as Western Europe, this information could be reported electronically [6].
This represents a new approach to syndromic surveillance that might provide more data of better quality than what is available today, and at an earlier stage.

2. Objectives

Real-time reporting of symptom data by patients might clearly benefit medical communication and treatment processes on a dyadic/individual level, and symptom based surveillance and management on a population level. However, patient attitudes related to symptom reporting and use of symptom data for consultation and surveillance purposes in primary healthcare has largely been unexplored.

This paper presents an investigation of people’s experiences and attitudes related to distinct stages in the process of communicating symptoms in a primary healthcare setting: a) Attitudes and experiences with regards to acquisition of information related to symptoms, b) attitudes towards computer based communication of symptoms to the GP and how they prefer to carry out such reporting, and c) attitudes towards storage, use and presentation of symptom data.

3. Methods

Data collection was performed by distributing 83 questionnaires among the population of the city of Tromsø in Northern Norway during March 2009. A convenience sample was drawn by approaching people directly, and having them fill out the questionnaire immediately after agreeing to participate. Data was collected at diverse public locations, including a student hostel, the university library, a research centre, the airport, and various social venues (cafés). However, attitudes towards health and information technology could be envisioned to vary based on age, gender, and level of education [6]. The sampling procedure and the selection of locations for distributing the questionnaire aimed to approximate a representative distribution of these demographic variables in the sample. For instance, visiting university locations to increase the amount of younger respondents under education, and two particular cafés to increase the amount of elderly people and people with less or none education. Respondents were at least 16 years old as this is the requirement to consent to participation in health related research projects in Norway. Foreigners received the questionnaires in English.

The questionnaire used consisted of 12 items, which represented a combination of multiple choice and free text (comments), and prioritization of alternatives. The questionnaires were completed anonymously and contained no questions regarding personal health status. A questionnaire used in another study was used as a template for the survey development [6]. Since the use of Internet for health purposes are affected by gender, age, education, nationality and visits to the GP during the past year [6], these variables were included in the study. In addition, participants were asked several questions aimed at whether or not they acquired information about symptoms and problems prior to the medical consultation and their attitudes towards providing their GP with symptom information using electronic media. The last questions focused on attitudes regarding storage, use and presentation of symptom data. The questionnaires were pilot-tested on three students and five researchers, which resulted in modifications of three questions. Under the next pilot-test towards researchers no suggestion to modification came up. The questions can be found at http://telemed.custompublish.com/getfile.php/1555219.357.ufxupxfaq/Questions%20for%20symptom%20reporting.pdf.

Respondents spent 5–10 minutes completing the questionnaire. The person distributing the survey was available for answering questions from the respondents, for instance in case of misunderstandings.

Three questionnaires were excluded from the analysis due to incomplete answers. Selections of free-text responses were subject to a content analysis identifying dominant themes related to the specific questions. Research objectives were investigated by descriptive statistical analyses. A binominal logistic regression analysis was performed to investigate which variables could predict the respondents “attitude towards providing symptom information prior to a medical consultation using electronic media”. The attitude variable was recoded to distinguish between uniquely positive individuals (responded “yes”) and undecided or negative individuals (responded “maybe” or “no”). Variables were selected based on two strategies: First, from theory and former research demographic variables known to be related to health related attitudes and behaviours [6]. This prompted inclusion of the demographic variables: Age (1–5 intervals), Gender (female/male), and Level of Education (1–4 intervals). For specification of the intervals see Table 1. Second, a bivariate correlational analysis was performed to indicate potential predictor variables in the collected material. No interaction terms were evaluated due to the small size of the study. Variables with a statistically significant (p < .05) value were retained in the model. SPSS 16.0 was used for the statistical analysis.

4. Results

4.1 Demographics

A total of 80 questionnaires were included in the survey. The sample characteristics are shown in Table 1. The youngest participant was aged 16 years, the oldest 70 years, and the age mean was 36.7 years. A higher proportion of females (81%) than 

<table>
<thead>
<tr>
<th>Table 1</th>
<th>Numbers of participants in each category of the sample. Tromsø, Norway, March 2009</th>
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<tbody>
<tr>
<td>Nationality</td>
<td>Norwegian: 77</td>
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<tr>
<td>Gender</td>
<td>Female: 36</td>
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<tr>
<td>Education</td>
<td>Primary and lower secondary school: 5</td>
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A) Acquisition of information prior to the medical consultation
61% used the Internet to check out or “Google” their symptoms prior to a consultation (41% frequently, 20% more infrequently) 35% never acquired information about their symptoms prior to the consultation

B) Providing information electronically prior to the medical consultation
61% were willing to provide information about their symptoms to the GP’s office as soon as possible after falling ill (“yes”) 35% were undecided (“maybe”) 4% negative (“no”)

C) Storage, use and presentation of symptom-data
84% were willing to have their reported symptom data stored in their EPR at the GP office. 76% agreed that the GP might access and present the symptoms together with the prevalence of matching diseases in order to assist the diagnostic process during the next consultation. 43% were willing to report symptoms directly into a surveillance system without going through the GP’s office/system, 49% were negative, while 9% did not reply to this question

Note. Nagelkerke $R^2 = .077$

### 4.2 Patients’ Acquisition of Information prior to the Medical Consultation

The majority of the respondents used the Internet to check out or “Google” their symptoms prior to a consultation (Table 2). Of those who used the Internet, 16 respondents commented by free-text that they conducted this kind of search because the information on the Internet is available and easy to access. Sixteen respondents commented that they conducted this search to clarify their symptoms, and to get a preliminary idea about the nature of their problems. Nine respondents commented that they used the Internet to diagnose themselves, where six of these nine emphasized that they did not intend to consult a GP if they were successful. Of those who never used the Internet in this manner, ten respondents commented that this had been unnecessary because they had not been ill, or that they had no unrecognized symptoms. The remaining eight respondents expressed a lack of interest in symptoms, or that they had no recognized symptoms. The majority of the respondents (68%) had visited their GP during the last 12 months, while 31% had not. Also, the majority (78%) of the respondents usually had a clear opinion about their diagnosis before they visited the GP, while 14% answered “seldom” and 5% “never”.

Respondents were asked to provide their information sources for their “opinion about the diagnosis”, where we recorded the four most frequently picked. Sixty-nine percent answered that they made use of previous experience, 55% discussion with family, friends, and colleagues, 41% based it on information from the Internet searched, and 19% medical books. Four respondents commented that they had some level of medical education. Information based on newspapers represented 9%, TV/radio 8%, and information from pharmacies 8%.

### 4.3 Patients Providing Information Prior to the Medical Consultation

The majority of the respondents were willing to provide information about their symptoms to the GP’s office as soon as possible after falling ill (Table 2). Only one of the positive respondents commented on why, and that was because “this is the future – it has to be done like this”, while two skeptical respondents found this approach too time consuming.

The respondents who were open to reporting symptoms electronically (i.e., answered “yes” or “maybe” on this item) were also asked to indicate how they would prefer to provide the GP with this information. Respondents could choose between e-mail, mobile phone Internet service, waiting room computer/PDA, or web-interface. Thirty-nine percent preferred e-mail, 25% preferred web-interface, and 13% preferred the mobile phone Internet service (WAP). Thirteen percent preferred to provide this information by a computer or PDA at the GP’s waiting room.

In addition to the demographic variables included in the prediction model, the bivariate correlation analysis resulted in the inclusion of two variables for the regression analysis. The variables were significantly correlated with the dependent variable ($p < .05$), while showing no significant intercorrelation. These were “Medical visits last twelve months” (yes/no), and “Pre-consultation use of the Internet for males (58%) reported having visited the GP in the last twelve months.
the purpose of collecting information about the problem" (yes/no). Since the research procedure was an exploratory approach and the goal was to extract few potential predictors, we chose to perform a forward stepwise analysis. The regression analysis showed that the attitude towards providing symptom information prior to a medical consultation was predicted by “Medical visits in the last twelve months”. The odds ratio \( \exp(B) \) from Table 3 tells us that respondents who have visited their doctor in the last year are almost three times more likely to be uniquely positive about providing symptom information by electronic, mediated channels, compared to those who reported no visits to their doctor in the last year. No other variables contributed significantly to the model \( p < .05 \), which indicate that the relationship between the dependent and independent variables could also have been investigated by Chi-square analysis. The model accounted for approximately 8% (7.7) of the variance of the dependent variable.

### 4.4 Storage, Use and Presentation

The respondents were willing to have their reported symptom data stored in the EPR at the GP office. In addition, they accepted that the GP might access and present the symptoms alongside the prevalence of matching diseases in order to assist the diagnostic process during the next consultation (Table 2).

Regarding the storage of reported symptoms in the EPR, four respondents commented that this would provide better documentation related to their problems, and that this would be a good way to update their personal health record. Further, four respondents commented that the fact that the GPs would be able to repeatedly access the reported symptoms could play a positive role in having their case thoroughly investigated by the GP. Sixty-one percent of respondents indicated that they would report the symptoms in the EPR, four respondents commented on the importance of anonymity, and one expressed concerns about quality. Three respondents suggested that a system receiving symptoms from patients should also provide a response to patients with regards to possible diagnosis and treatment. The trustworthiness of different information sources in presentation of surveillance data was investigated by asking respondents to select up to three sources that they would trust when being presented this type of information. Eighty-nine percent answered that they would trust their GP, 70% the Norwegian Institute of Public Health, and 60% the local university. Only 10% would trust the Internet, 6% TV, 3% Google Flu trend, and between 1% and 3% would trust local or national newspapers.

### 5. Discussion

This study attempted to document patient attitudes related to two different aspects of electronic pre-consultation symptom reporting: Attitudes and experiences related to the primary care consultation and attitudes related to use of symptom-data for purposes of symptom based surveillance. The results indicate that the respondents were predominantly positive with regard to providing symptom information electronically to their GP. Sixty-one percent of respondents indicated that they were positive, while 35% indicated that they might be willing to do this immediately after feeling ill and when seeking help. Over half of these respondents indicated that they would prefer to use e-mail or a web-interface to perform this task, rather than WAP-interface or technology in the GP-office’s waiting room. This implies that people are motivated to use the most available technologies, and the technologies with which they are accustomed. Also, it points to a preference towards home-based solutions. It is important to note that a former study investigated preferences for home-based symptom screening in cancer patients (specialist care) included touch-tone telephone as an alternative to completing questionnaires over Internet [31]. Here, even patients with Internet access preferred using the telephone to Internet-based approaches. This supports the notion that people prefer familiar technologies for health-purposes. The current study did not include the telephone, as we did not consider it a realistic alternative to comprehensive data-collection in Norwegian primary care.

It is important to note that an expression of positive attitudes towards electronic symptom reporting does not guarantee accomplishment of the benefits suggested by this text (e.g., efficiency and quality of doctor-patient communication, improved surveillance data, etc.). There are numerous obstacles that could be envisioned to prevent such benefits even though patients are positive, including organizational, situational, and technical issues. However, this is an emerging topic, and there is little doubt that positive patient attitudes are among the most important factors needed to achieve these benefits.

We also investigated attitudes towards storage and use, either for documentation, further investigations or for symptom based surveillance. Generally, the respondents accepted that their symptoms could be stored in the EPR system. This would enable the GP to access these data at future
consultations in order to assist in the diagnosing process. For instance, data could be presented alongside the prevalence of local diseases matching these symptoms. Repeated access by GPs to symptom data could also aid the thorough investigation of specific cases. A system for pre-reporting of symptoms may also analyze data and provide diagnostic aid of patients, including links to further reading. This will serve to prepare patients and facilitate participation in the treatment [32]. To assist medical decision making, individual patient characteristics/symptoms can be matched to information and advice regarding recommended examinations [33] and solutions to problems and diagnoses for comparable patient’s cases [34–36]. Interestingly, the majority of the respondents were skeptical regarding reporting symptoms directly to a surveillance system without going through the GP’s office. However, this still might be a possible approach since the 43% expressing a positive attitude could be sufficient to provide a representative outbreak picture. For example, 0.1% or less of the total population that reports on influenza-like-illness via the Internet in Netherland, Belgium and Portugal show the same trend as the incidence curves of the traditional system of sentinel networks (37).

In predicting patient’s attitudes towards performing pre-consultation symptom reporting, it appears that “medical visits (last twelve months)” is a central variable. The variable is included in the regression model (Table 3) as a significant predictor of respondents’ attitudes towards providing symptom information. However, this model only explains about 8% of the variance in the dependent variable. Thus, several other variables not included in this study are equally relevant in explaining people’s attitudes towards providing symptom data electronically. For instance, inclusion of variables such as health status and other specific health-related attitudes would be necessary to understand this relationship better.

When discussing the appropriateness of symptom reporting prior to the medical consultation there are several interesting issues that could be explored. For instance, the accurateness and validity of reported data might be questioned. However, as indicated from studies of momentary symptom ratings, there is little reason to doubt the accurateness of such data when compared to average or retrospective ratings [8, 9]. With regards to the validity of data gathered through electronic channels research on computer-mediated communication (CMC) has indicated that mediated communication is often associated with higher levels of self-disclosure [38]. These findings have been replicated for health relevant communication, in both pre-clinical and clinical settings [39–44] and anonymous, peer-support settings [45]. In sum, people appear more willing to disclose socially sensitive health information using CMC. They report more and/or more serious symptoms, and they comment that it feels easier disclosing their health problems in an anonymous setting. It is worth mentioning that this is apparently irrespective of whether the information will be seen by health professionals at a later stage (e.g. [40]). Such findings, along with the positive attitudes expressed by potential users in the current study, support the viability of a patient-centric symptom-reporting tool.

The presented study utilizes a non-probabilistic sampling technique, and this limits the generalizations that can be drawn from the data. However, some efforts were made to ensure that the sample was not misrepresenting the general population. Except for the youngest age group that is a bit overrepresented, we believe that the approximate representation with regard to gender and age allows for generalization to a certain extent [46]. With regards to level of education, we acknowledge that people in the lowest of the four education groups appear to be somewhat underrepresented in our sample compared to 2009 statistics for the municipality [47]. The percentages for the highest education group is in accordance with the 2008 statistics for Norway, and approximately in accordance with data from eight other West-European countries, as well as Australia and New Zealand [48].

Further, large studies provide results that support our findings. First, we found that 68% had visited their GP during the last 12 months, while this number was 71% for the general Norwegians population in 2006 [49]. Second, 61% used the Internet to check out or “Google” their symptoms prior to a consultation, which is in accordance with previous findings where 59% of Norwegians and 62% of the Danish population used Internet for health purposes [6]. Third, more females than males in our sample reported having visited the GP during the last twelve months, which reflects data from the larger population regarding the use of health services [49].

The current results indicate that primary care respondents are willing to report symptoms, which could help improve primary care consultation and syndromic surveillance. In a system for patient-centered symptom reporting the data would be primarily produced in order to improve the focus and quality of the medical consultation, while at the same time being used for the purpose of surveillance. This could simplify the production of surveillance information of high quality. However, we also know that there is a considerable gap between people’s intentions/attitudes and their behavior [50]. Consequently, there is a need for additional studies that investigate if these patients actually would report symptoms electronically in primary care. As to the willingness to report symptoms, encouraging experiences have been gained from large-scale volunteer efforts. This includes free and open source software development, distributed computing, and the Wikipedia [51]. Also, cancer patients completing questionnaires electronically are “overwhelmingly positive towards using it to benefit others”, whether to improve patient care or for research [1]. Evidence directly relevant to syndromic surveillance has also been published. Self-reported information from patients and families has been demonstrated at an emergency department waiting room of a tertiary care children’s hospital for use in disease surveillance [52]. The results showed that “disease category assignment based on patient-reported information was significantly more sensitive in correctly identifying a disease category than data currently used by national and regional disease surveillance systems” (52, p 765). Further, epidemiological data has been gathered from patients using web-based questionnaires [53], and consumers have demonstrated willingness to participate in surveillance...
by using websites which prompt users to register symptoms (e.g., WhoIsick.org, Sicklike.me, etc.) [54]. The Great Influenza Survey (GIS) in Netherland, Belgium and Portugal, which is based on weekly voluntary online participation of the population, further strengthens this impression [37, 55, 56]. We believe that future disease surveillance systems will be a combination of patient-centered symptom reporting systems, and surveillance systems utilizing other formal and informal sources.

6. Conclusion
The results of this study support the applicability of electronically mediated pre-consultation systems both for primary care consultation and for use in symptom based surveillance, including real-time surveillance. This is an indirect conclusion based on positive patient attitudes to central aspects of such systems. First, patients were familiar with using the Internet for health purposes. An example is the acquisition of information related to their symptoms prior to a consultation. Second, patients were positive towards providing symptom information to the GP's office as soon as possible after falling ill. Most patients preferred to use e-mail or a web-interface, which are the most available technologies, and the technologies with which they are accustomed. This points to a preference towards home-based solutions. Third, patients were positive that their symptoms could be stored in the EPR system and used at future consultations in order to assist in the diagnosing process. Further, they agreed that the GP might access their symptoms together with the prevalence of local matching diseases (local surveillance information) in order to assist the diagnostic process during future consultation. However, further studies are needed to address these issues in more depth.

Acknowledgments
This study has been partly funded by grants from the Health North Authorities (TFP-661-07), Norwegian Research Council grants (1749349), and The Norwegian Centre for Integrated Care and Telemedicine (NIT). We want to express our thanks to colleagues and the participants for their contributions, Per Egil Kummervold, NST, for useful advice, support and feedback, Gunnar Ellingsen for his involvement in the preparation of the study, and Alexander Horsch for useful advice, support and feedback, both from the Telemedicine Research Group, University of Tromsø. We add special thanks to the reviewers of Methods of Information in Medicine.

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