

# Development of a computerized tool for self-assessment of subjective symptoms that can be integrated in a Personal health record

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**Abstract.** More than 10.000 people die from cancer every year in Norway. During the last stages of the disease, the aim of the therapy is no longer to prolong the life of the patient but rather to focus on the patient's quality of life. For the last 5 years the palliative care research community in Trondheim and Oslo have developed PAT-C, a computerized tool for assessment of patients subjective symptoms. This tool has earlier been implemented on a PDA platform and recently as a standalone application for PC's. We now aim to further develop the PAT-C application to become an application that adapts the questions to the capabilities of the individual cancer patient and to integrate PAT-C as a component for self assessment and reporting in the patient's personal health record. We here present the outline of this project.

**Keywords:** Self-reporting of subjective symptoms. Palliative care. Personal health records. Health informatics.

## 1 Introduction

The cancer risk is steadily increasing, and more than 24 000 Norwegians were diagnosed with cancer in 2004 [1]. Among these, about 50% will be cured, and the rest will be in need of palliative treatment at some stage of their disease trajectory [1]. Cancer typically affects the older population, and thus most palliative patients will, in addition to their cancer, also have other co-morbidities [2]. The treatment goal in the palliative phase of cancer diseases is to relieve symptoms and improve quality of life [3, 4]. Most patients in the palliative phase of their disease experience several symptoms at the same time, and different symptoms may dominate at different stages of the palliative phase [5]. In general, the health care system does not function optimally with respect to detecting and treating symptoms in palliative care patients [6].

Despite huge efforts during the last 10-15 years, pain still remains inadequately treated in a huge proportion of the palliative care population and in spite of many and increasing number of treatment options [7]. There are probably many factors that contribute to this rather unsatisfactory situation, but the inadequate assessment of

subjective symptoms including pain is probably one of the most important [8]. This may relate to: A. Lack of consensus on how to assess subjective symptoms, B. Assessment of subjective symptoms has not been integrated into clinical practice, C. The existing tools are inappropriate for clinical use, D. Health care professionals lack the necessary skills to use the available tools for symptom assessment, E. The assessment results are not available where the clinical decisions are taken. The existing assessment tools also have deficiencies with respect to measurement capabilities [9]. This has consequences for the quality and quantity of clinical research on symptom therapy. For example, meta-analyses of pain treatment have been difficult to conduct due to the use of different outcomes, i.e. different pain questionnaires in the different studies [10].

For the last 5 years, the palliative care research communities in Trondheim and Oslo have been developing PAT-C, a computerized tool for patient's reporting of pain and other subjective symptoms. The application has undergone an iterative development. Currently, the first clinical study utilizing computer-based assessment is now running. Data from 1000 Norwegian palliative care patients will be collected May-December 2006. During the development of the PAT-C-tool, it has become evident that much work has yet to be done on the development of optimal software solutions fitting the palliative population with its special characteristics.

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## **2. Further development of an interactive questionnaire for self-reporting**

The aims for the planned activities are:

1. To create a computer version for assessment of pain localization
2. To define the optimal characteristics of a Computerized Assessment Tool for patients receiving palliative care
3. To study the effect of a Computerized Assessment tool on clinicians decision making process

In the next iteration of PAT-C both architectural considerations, the principles of user-centred design and item-response theory will be taken into account, this to meet

- Personal health records as an emerging tool for patients and
- The special needs of patients receiving palliative care
- The need to adjust the questions to each individual patient by use of item response theory (IRT) and possible of artificial intelligence techniques.

We here will describe and discuss general design considerations, and which plans we have for the further development of PAT-C integrated in the Personal health record but also as a standalone application.

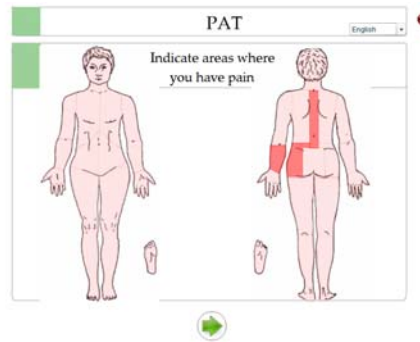
## 2.1 Design considerations

During previous iterations of PAT-C, several challenges have been identified, and solutions have been proposed and implemented. These are summarized in table 1.

**Table 1.** Challenges when implementing the PAT-C.

Challenge	Solution
Hit the right spot for answering	Doubled the size of radiobuttons class
Keep the patient focused	Presents one question at the time
The patient will be tired	Only able to go forward, not able to review
Readability	Question text-size of 30px
Indicate pain localization	Creating a clickable bodymap with 36 regions

**Fig. 1.** Clickable BPI body-map.



In a pilot-study before the official data collection in PAT-C, we assessed the use of Tablet computers to see how the patients reacted to the software developed and the use of computers for answering questions regarding their pain and physical functioning. The response from the 20 patients in the pilot study was as follows

- 9 had not used computers before, 11 had used computers
- 11 persons preferred using computers for answering, 5 persons had no preference and 3 would prefer using paper and pen (1 missing)
- 19 persons had no problem reading the text (1 missing)
- 16 persons had no problem clicking the radiobuttons for answering. 3 had problems (1 missing)
- Everybody understood the concept of radiobuttons for answering
- 18 persons had no problem understanding how to use the body map, 1 had problems (1 missing)

These responses are promising regarding the validity of the PAT-C tool. There are many considerations for securing the validity, and the user interface is a key component for that in computer-based testing [11]

## **2.2 Creating a computer version for assessment of pain localization**

Clinicians rely on information about pain intensity and localization in their diagnostics. For clinical as well as scientific purposes information on pain localization is of great importance in order to understand, classify and treat the pain. Most clinical studies assess pain intensity but not pain localization. Different types and localizations of pain are thereby collapsed into the principal outcome in these studies.

The Brief Pain Inventory (BPI) is recommended by the European Association for Palliative Care (EAPC) as the principal tool for assessment of pain in palliative care [10, 12]. In addition to its 4 items on pain intensity and 7 items on the interference of pain with functioning, the BPI also includes a body map. This is to be completed by the respondent in order to assess the localization of their pain (Figure 1). The body map is of value in the clinics but of very limited value in research due to the difficulties in quantifying the drawings systematically. Such drawings on a paper questionnaire also fit poorly with electronic medical records, which imply that the information is not fully utilized in daily clinical practice. As far as we know, no systematic attempts to computerize the body map have been performed.

## **2.2 Develop a model and architecture for integrating a self-assessment tool in the Personal health records**

We will describe a model that enables exchange of information between patients and professional care providers. Both patients and providers will be able to take the initiative to start registering symptoms. Both patient and provider will benefit from having access to longitudinal data. The data will belong to the patient, and he will decide who shall get access to the data.

## **2.3 Development of a questionnaire tool that uses item response theory to adapt the questions to the user.**

Palliative patients have high level of symptoms, high age, co-morbidities and decreased performance status [3]. This makes the completion of lengthy questionnaires to a burden that can affect their quality of life. We will use techniques from advanced psychometrics (item-response theory (IRT)) and artificial intelligence (case-based reasoning (CBR)) to make the completion of the questionnaire less of a burden for the patient. We will develop an application that uses these techniques to minimize the amount of questions asked to the patients, as well as help the clinician in the decision making process.

### 3. Conclusive remarks

In this paper we have outlined the work that will be undertaken to make PAT-C a mature and advanced application for assessment of subjective symptoms in palliative care.

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