Visualizing Complex Patient-Reported Outcome Data to Support Follow-Up of Head and Neck Cancer Patients

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ABSTRACT
In the follow-up of patients with head and neck cancers (HNC), Patient-Reported Outcomes (PRO) are insufficiently used as immediate treatment feedback although they could support both physician-patient communication and physicians’ decision making. Physicians’ everyday work in routine clinical care is often characterized by lack of time, workload pressure and inadequate resources. To allow for efficient and effective review of the complex heterogeneous outcome data, a hierarchical information structure was developed with regard to a dashboard paradigm for an interactive tablet-based system. Applying a user-centered process, a structure of top-level categories and their contents was constructed in cooperation with physicians specialized in Otolaryngology. These categories contain both questionnaire scores and standalone metrics with indicators for need of intervention. Considering the suitability of a patient overview dashboard, corresponding design guidelines have been identified. The developed application, which is currently used in the follow-care of HNC patients in a prospective non-randomized controlled monocentric care trial, has been iteratively tailored for routine clinical care using a rapid prototyping approach. A particular focus was on the form factor, interaction capabilities and limitations of tablet computers regarding the overall usability of the dashboard.

CCS CONCEPTS
• Applied computing → Life and medical sciences → Health care information systems; Health informatics • Human-centered computing → Human computer interaction (HCI)

KEYWORDS
Patient-Reported Outcomes, Patient-Centered Care, Clinical Decision Support, Head and Neck Cancer

ACM Reference format:

1 Introduction
In recent years, Patient-Reported Outcomes (PRO), the assessment of the health-related quality of life using instruments completed by the patient [5,6], have been identified as a means for direct care to improve the communication of patients and physicians and the decision making regarding therapeutic measures [11], resulting in an overall increase in survival rates [1]. This is particularly relevant to patients with head and neck cancer whose therapy is accompanied by functional impairments, e.g. a surgical procedure on the throat may severely affect the vocal cords of the patients. In consequence, patients are often unable to adequately articulate in a timely manner. Thus, they do not necessarily communicate all relevant information to their physicians—whose everyday work, on the other hand, is characterized by lack of time, workload pressure and inadequate resources [14]. As a result, the attending physician may not identify all critical health-related issues in the few minutes available to him for the consultation with the patient. This can potentially lead to insufficient or even harmful intervention measures.

Due to a variety of challenges and barriers, however, the use of Patient-Reported Outcomes in routine clinical care has not been widely adopted by health care institutions: Additional time constraints, issues with the interpretation of PRO data, usability concerns, inadequate integration with clinical practice guidelines, and even physicians’ resistance against workflow changes, to name only a few, contribute to missed opportunities [8,11,13]. These major issues are addressed by the design process, resulting guidelines and the developed system presented in this paper.
1.1 Current Follow-up Procedure

After a tumor has been diagnosed, the primary treatment is initiated as soon as possible. Usually, it includes a primary surgery to remove the cancer tissue, radiation therapy, and chemotherapy. Depending on the circumstances and the particular tumor, not all of these measures may be feasible or necessary. In the first 2 years of the follow-up treatment, consultation appointments with the physician are usually set at least every 3 months [15,16]. After that biannual check-ups are common. The process of a typical follow-up appointment is illustrated in Figure 1.

Figure 1: Standard follow-up procedure

Commonly, patients wait at least a few minutes after arriving at the clinic. During this time, the physician prepares for the consultation by reviewing the patient’s paper-based case file as well as the patient’s health record in the hospital information system. The paper-based case file is usually handwritten by different physicians because physicians are not permanently assigned to certain patients. Instead, a currently available physician is assigned to an appointment. In consequence, the combination of reviewing information from multiple sources in the few minutes available poses a major challenge in clinical routine care. Furthermore, changes in the schedule may increase the waiting duration for the patient to more than one hour. This can be a result of emergencies or of generally high workload and an accordingly tightly timed schedule.

In the following consultation, the physician must determine the current health status of the patient, document issues and adverse events, and take measures where necessary. The decision making is individual per patient: the complete therapy history and relevant health conditions such as comorbidities must be considered in order to take appropriate measures. Additional therapy measures may be required if not all cancer cells were destroyed in the primary therapy.

1.2 Scope of Research

As part of a clinical research project based on a prospective non-randomized controlled monocentric care study [20], this paper is addressing the question of how PRO feedback data should be presented to physicians in order to appropriately support the patients’ treatment in the course of follow-up care. Since the overall goal of the clinical project is to assess the effect of immediate tablet-based feedback on the treatment outcome, both patients and physicians interact with tablet computers in the course of this study: The patients use them to fill in the patient questionnaire tailored for HNC. This is done in the waiting area after patients have arrived for their appointment. Physicians, on the other hand, use tablets to document the diagnosis and performed therapy measures. Additionally, they fill in a checklist in the course of the consultation with the patient. Previously entered data may then be used by accessing a single platform in the course of the preparation for the appointment or during the consultation itself.

The different types of data entry forms are composed of constructs respectively measures of different established questionnaires (further discussed in section 1.3.) which causes a notable challenge: Whereas individual clinical scores are usually validated and their assessment is well-defined, composition and visual presentation of multiple constructs in a meaningful manner are mostly ambiguous—especially in regards to the interactive system. In general, it must be designed to allow for efficient, effective and satisfactorily usage and conform with the physicians’ mental model, as defined in [10], to achieve acceptance among its users.

From a safety-critical perspective, it must be ensured that the therapy feedback does not have a negative effect on the patients’ treatment, e.g. due to poor integration into established workflows or by inferring incorrect and harmful therapy measures. Ultimately, only a well-adapted system may empower physicians to make well-informed decisions based on a holistic health status overview in the follow-up care of HNC patients.

Therefore, this study’s objective is to determine an adequate structure in which the vastly heterogeneous constructs of the different questionnaire are aggregated and presented to the physicians during the consultation with the patient. This includes both a semantically meaningful information hierarchy and a matching user interface in which this structure is displayed in order to conform with the previously stated usability and contextual requirements. Adequate integration of the system into the physicians’ work routine is particularly important to prevent interference with established processes and workflows.

1.3 Questionnaires in Use

The patient questionnaire used in the study is based on the International Classification of Functioning, Disability and Health
(ICF) core set for HNC (ICF-HNC) [9,23] and includes a variety of measures to assess the patient’s health status in terms of ingestion issues and abilities, overall pain, mental issues, and social burdens, as well as comorbidities and extra burdens relevant to the evaluation.

In contrast to these self-assessed measures, the physicians’ checklist is used to document functional impairments, needs for intervention from the physician’s perspective and adverse events which are documented according to the Common Terminology Criteria for Adverse Events (CTCAE) [18]. Tumor diagnoses and therapy measures are documented in separate pages of the application.

The aggregation and presentation of this data pose major challenges. Differences of the questionnaires individual measures complicate the design of a generalizable presentation form. The sheer number of items itself results in a complexity that strongly affects the possibility of an overview dashboard where the data is presented in detail and completeness but also comprehensible and visually distinguishable on devices with smaller screens such as standard tablet computers. The patient questionnaire alone comprises a total of 11 different scale ranges and question types which unfortunately cannot be adapted without impairing construct validity. For example, the patient’s pain is measured in a standard 11-point Numerical Rating Scale (NRS) [4], the Patient Health Questionnaire (PHQ-9) [7] which assesses the mental health uses a 4-point scale, and other questions require a numerical or text input e.g. the patient’s weight. Furthermore, the different calculated scores differ in their value range and scale direction. Some of these scores are better if they are lower, some if they are higher, thus contributing to existing consistency issues.

Additionally, a digital presentation of the results was not explicitly intended when these different measures were designed. Although digital questionnaires and feedback systems exist for some of these instruments, they are most commonly used in paper-based forms.

2 Methods

The overall development process of the system is based on the human-centered design process for interactive systems as specified in the ISO standard 9241-210:2010 [12] and makes use of Contextual Design methods [3]. It includes the following process steps listed in chronological order:

1. **Contextual Inquiry and work modeling**: based on interviews with physicians of the Department of Ear, Nose and Throat of the University Medical Center Schleswig-Holstein (UKSH). In addition, trial specific requirements derived from the study protocol are considered in cooperation with epidemiology experts of the Institute of Social Medicine and Epidemiology of the UKSH.

2. **Specification of system requirements**: insights of the preceding step are transformed into specific requirements in order to guide the design and implementation process.

3. **System implementation with rapid prototyping**: Individual pages and components are designed and implemented in short iterations in a participative design process which allows for continuous formative evaluation. Consequently, opportunities to improve the system and adequately adapt it to its context of use may be incorporated successfully. This approach has been chosen due to the previously stated time constraints in the physicians’ day to day activities. For this study, the more regular and frequent feedback was better suited than more traditional design processes with fewer but prolonged iterations and considerably more comprehensive formative evaluations—this would have been difficult both to organize and to carry out in the highly dynamic and difficult to plan clinical daily routine.

4. **System evaluation**: The usability of the developed system is evaluated. If the requirements are met, the development is finished. Otherwise, the system must be improved in order to be adequate for its intended purpose.

The following section will not explicitly present detailed results of the contextual inquiry and work modeling but focus on derived design guidelines and the developed system with its key aspects.

3 Results

In the rapid prototyping phase, 8 physicians of the Department of Ear, Nose and Throat of the UKSH took part in the participative design and provided feedback. During this period, which lasted about 4 months, it was determined that the heterogeneous data should not be displayed in its entirety on a single page. As previously stated, the sheer amount of measures would impair the perception and interpretation of available information. Instead, the different measures were assigned to different categories on a semantic basis in order to allow for grouping and summarizing of information.

For the presentation, several guidelines to reduce visual complexity in order to support information perception and interpretation have been derived from the requirement analysis, literature review and physician’s feedback. On this basis, a patient overview dashboard was iteratively designed and implemented.

3.1 Information Hierarchy

The physicians identified a total of 8 different top-level categories for the available information from the patient questionnaire and the physicians’ checklist as well as diagnosis and therapy data:

- **Patient Profile**: This category gives an overview of the tumor diagnosis and performed therapy measures (surgery, radiotherapy, and chemotherapy) as documented by the physician.
- **Generic**: This category covers the health-related quality of life, pain and fatigue scores.
### 3.2 Design Guidelines for Visualizing Patient-Reported Outcomes

With consideration of the various issues of the data, as explained in section 1.3, the following design principles and guidelines have been derived in the rapid prototyping phase:

- **Overview first, details on demand** [21,22]. In order to reduce complexity, the relevant information should be grouped and summarized on a semantic basis and displayed on an overview page. Details such as comprehensive score trends should be made available in a separate detail page for each of these groups—they can be viewed on demand e.g. if intervention need is suggested by a measure.

- **Flat navigation hierarchy** [19]. To keep the number of interaction steps as low as reasonably possible and to prevent orientation issues due to complex navigation hierarchies, the information displayed on detail pages should not be further nested.

- **Scores on the overview page**. Depending on the number of scores that should be displayed, the screen real estate may not suffice to display these as charts. Instead, scores should be presented as numerals with their respective maximum. The optimal values and direction of scores should be indicated, especially if they are not identical. Additionally, score trends may be visualized by indicating the change to the previous examination. This ultimately reduces the amount of simultaneously displayed information while important clues for data interpretation are brought to attention.

- **Consistency** [2,17,22]. Although the information of the different measures may be of different quantity and quality, the interaction with it should be as consistent as possible. Even if the screen’s real estate might allow for displaying charts for a few scores while displaying other scores as numerals, this may have counter-productive effects such as incorrect assessment of a measure’s importance.

- **Highlight only critical measures**. If intervention is required according to a measure, it should be highlighted as such. On the other hand, apparently normal measures should not explicitly be highlighted as “good measures” to prevent distraction and false positives which might lead to insufficient or harmful treatment.

- **Multicodal display of measures**. Especially for users with visual impairments (e.g. color vision deficiencies), the assessment of the measures should be supported by multicodally communicating their criticality. For many situational conditions, such as challenging lighting in the environment, this can benefit both impaired and non-impaired users.

- **Authority of physicians**. Physicians must retain control of therapeutic measures since they must take responsibility for all measures performed in the course of therapy. Thus, recommendations must be presented as such and must not give the impression of being mandatory.

### 3.3 Patient Overview Dashboard

In accordance with the previously stated design guidelines, the information hierarchy was mapped to a page structure with an overview page and category-based detail pages. Each of the previously identified categories (see section 3.1) is represented by a tile in the overview page of the dashboard. These similar sized tiles display the categories’ most important information regarding the patient’s health as shown in Figure 2.

![Figure 2: Overview dashboard in the interactive tablet-based system for review of the patient’s health status](image_url)

If a category includes numeric measures such as scores, this is displayed as numerals with trends and indicators to support the interpretation of the displayed values. Other measures are presented in text form, e.g. the Patient Profile or the Risk Factors and Comorbidities.

If any one measure of a category suggests intervention need, this is indicated for the respective category. In addition to a textual notification, the corresponding tile is then highlighted with a slight red background gradient, the Details button is highlighted, and a warning icon is displayed. This is illustrated in detail in Figure 3.
Since the severity of an issue usually cannot be determined reliably, no distinction between categories with few and many critical measures is made in order to prevent possibly harmful neglection of some categories. After all, each measure that indicates a need for intervention must be thoroughly examined by the attending physician.

For further investigation of a category, the physician may navigate to the category’s corresponding detail page, e.g. the Nutrition detail page which is displayed in Figure 4.

Each detail page has a different layout, depending on the corresponding category’s measures. Scores are displayed in further detail by line charts which may include baseline or threshold annotations. Textual presentation is semantically grouped if it is reasonably possible. If a score allows for detailed conclusions, these are displayed textually alongside its chart as shown in the previous screenshot for the dysphagia score on the left side.

3.4 Feedback from Physicians

Current non-standardized feedback from physicians indicates an overall high acceptance of the system. Some physicians stated that the self-assessed health information of the patients not only provides a valuable addition to current standard work practices but also allows for better assessment of the patient’s condition.

In some cases, however, the system uncovered health-related issues such as mental disturbances that the physicians had not suspected if they had evaluated the patient’s state of health solely based on their consultation with the patient.

According to the physicians’ feedback, a different issue which is mostly caused by the physicians’ various levels of experience has been identified as well: Whereas the system raises awareness for potential issues and intervention needs, the optimal therapeutic measures remain unclear in some cases. Different physicians take different measures depending on their experience. As a result, patients with a similar course of disease and therapy may be treated completely different altogether.

4 Conclusion

During the course of an iterative design process with rapid prototyping, the vastly heterogeneous PRO data and treatment documentation data from physicians have been assigned to a total of eight categories for reviewing a patient’s health status. Although these categories and their measures are tailored for the treatment of HNC patients, they may be suited for other cancers or quite different diseases as well.

To display these different categories in a meaningful manner, a set of design guidelines was identified upon which a patient overview dashboard for the tablet-based system was developed. These guidelines, which focus on reducing structural and visual complexity as well as preventing incorrect treatment decisions and harmful prioritization of some issues, may be incorporated in other interactive dashboards used in healthcare since they are not explicitly targeted specifically at PRO-based systems.

The developed dashboard is used in the clinical trial to allow for a comprehensive review of the health status of HNC patients thus supporting the decision making in the individual treatment. So far, feedback from the involved physicians indicates a valuable addition to current work practices due to more detailed insight into health-related issues in comparison to the standard consultation with patients. The suitability of the system in the day to day practice of physicians is strongly dependent on an actual increase in treatment success. Consequently, for a conclusive verdict, this can only be determined in a long-term study. Furthermore, a thorough evaluation of the system’s usability and its integration into existing workflows must be conducted.

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