Quality of Information for Pruritus Research through Single Source

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Abstract. To avoid data redundancy and transcription errors in research databases single source concepts aim to reuse routine clinical data for scientific purposes. We therefore standardized the clinical documentation according to research needs and implemented respective forms within the EHR. We analyzed the current paper-based workflow to transfer data into a research database and envision our future electronic workflow with the integrated x4T single source system. We expect to increase data quality and reduce data entry times which will be evaluated in a future study.

Keywords. Clinical documentation, research database, single source, pruritus

1. Introduction

In clinical research databases the data is often redundant or even different to what is available within the electronic health record (EHR). In addition, the data entry is time consuming. To increase data quality and decrease the use of resources single source concepts aim to reuse routine clinical information for research databases [1]. This, however, implies the need to standardize medical documentation and enable an efficient data transfer into research databases. Different system architectures are mentioned in the literature, addressing the re-use of medical routine data in clinical research [2-4]. In our research group, we have developed a single source architecture using a mediator between EHR and electronic data capture systems for clinical trials. Data from the EHR is extracted and transferred to this system called x4T (exchange for Trials) [4].

In this paper we present our concept which is being piloted at the competence center for chronic itching (pruritus) in the dermatology department within the university hospital of Münster, Germany.

2. Methods

After collecting all pruritus documentation forms the routine data was analyzed according to their use for research. Through a consensus process with several medical experts a subset of forms and data elements was selected to define a minimum standard data set. The documentation and data transfer workflow for the research database was
depicted using event-driven process chains. For simplicity in this paper we present a shortened workflow using a Microsoft Visio flowchart.

The pruritus documentation forms were implemented in the local EHR ORBIS® by Agfa Healthcare using integrated form design tools. The forms which are documented by the patients themselves are collected via a web-based system that transfers data into the EHR [5]. As research database we have installed and extended our x4T-server [4] to allow a bidirectional data transfer.

3. Results

The form set, primarily used to collect pruritus data during routine treatment, which is then transferred into the research database for scientific questions consists of the following (see Table 1):

- Separate medical history forms for the first patient encounter and follow-up appointments. These forms collect mainly information about the diagnosis stating the exact type of pruritus and its quality. Also co-morbidities and the best therapy options are recorded.

- An initial patient questionnaire (Neuro-Derm) collecting information about the localization of pruritus as well as its (timely) occurrence, intensity and quality. Furthermore, it also asks about potential influences of the pruritus.

- Patient questionnaires generating scores about quality of life, anxiety, depression and pruritus intensity.

<table>
<thead>
<tr>
<th>Table 1. Documents used for Pruritus research – first patient encounter and follow-up.</th>
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<tbody>
<tr>
<td>Form Name</td>
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<tr>
<td>Initial Medical History</td>
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<tr>
<td>Follow-Up Medical History</td>
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<tr>
<td>Patient Questionnaire: Neuro-Derm</td>
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<tr>
<td>Patient Questionnaire: Dermatology Life Quality Index</td>
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<tr>
<td>Patient Questionnaire: Hospital Anxiety &amp; Depression Scale</td>
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<tr>
<td>Patient Questionnaire: Pruritus Intensity</td>
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The current workflow to transfer data from the EHR into the research database is paper-based and can be seen in Figure 1 (left side). Up to 200 patient visits per month need to be processed. The initial medical history is documented during the first encounter and relevant information is collected from the EHR and written onto a special paper-based pruritus data form by the physician. When the patient returns to a follow-up appointment, further data collected from the first encounter is manually transferred by an assistant from the EHR onto the pruritus data form. The completed form is then manually entered into the current excel-based research database. A summary sheet with selected information is printed for the next appointment and might be updated by the physician due to changes in the patient’s condition. The updated summary sheet and further follow-up information is then again entered into the research database and a new summary sheet is printed.

The future workflow making use of an electronic transfer from the EHR into the x4T research database is shown in Figure 1 (right side). Most of the data will be documented directly within the EHR, except of the Neuro-Derm patient questionnaire, which will be manually transferred into an electronic format by an assistant. Patients
documented within the EHR can be selected for the research database and directly be registered within the EHR. After the data has been checked and released by a physician it is automatically transferred into x4T and a summary sheet is send back to the EHR.

Figure 1. **Left:** Current paper-based workflow of the pruritus documentation process and data transfer into the Excel research database. **Right:** Future electronic workflow with transfer into the x4T research database.

### 4. Discussion/Conclusion

We analyzed the current workflow of the pruritus documentation and its transfer into a research database according to the single source concept and suggested a future process. The electronic workflow will save the manual data entry time and aims to increase data quality by reducing transcription errors and validating all data before the transfer.

A complete evaluation comparing the current and future workflow will be performed after our pilot stage. Additionally we will then prove the system’s scalability through a multicenter study, connecting different EHR systems.

### References


