Collect once - use many times
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Abstract. Collect Once – Use Many Times can possibly increase the research potential of clinical data from electronic healthcare records (EHR). The objective of this study was to achieve an increased understanding of the research potential of low back pain patients’ municipal EHR by assessing the data quality. This explanatory sequentially mixed-methods case study consists of descriptive- and content analysis. The descriptive analysis was based on data extracted from the municipal EHR. The indicators chosen were pain and physical function. Included subjects were low back pain patients in the Northern Denmark. For the content analysis, clinical notes from the municipal EHR was used. The descriptive analysis (n=172) showed that the outcome measure for pain was documented in 50% of the municipal EHR and the outcome measure for physical function was documented in 48% of the municipal EHR. The content analysis (n=5) revealed imprecise, inconsistent, and nonsystematic use of outcome measures. In conclusion, the poor data quality observed is a potential barrier for introducing the Collect Once - Use Many Times paradigm, which is a prerequisite for reusing clinical data for quality assessment and research purposes.

Keywords. Electronic Health Records, Physical Therapy Specialty, Data Curation and Data Accuracy

1. Introduction

The possibility to reuse patient centered data documented by healthcare professionals in the electronic healthcare records (EHR) has been an implicit expectation for more than two decades [1,2]. In spite of this, targeting reuse of data in the secondary healthcare sector for research, management, or statistical purposes is still in its infancy. Internationally, data reuse is referred to as the COUMT paradigm (‘Collect Once, Use Many Times’) [3]. Reuse of patient centered data requires high data quality, defined by data being conform, accurate, complete, and valid [4,5], thus COUMT is only feasible in mature EHR systems with a high degree of functionality and integration [6], through exhaustive terminology and information modelling [7–9].
In Denmark, municipal rehabilitation units generate large amounts of clinical data. However, whether these data can be used for research purposes is still not settled. Therefore, the objective of this study was to investigate the reuse potential of municipal EHR data in clinical research by accessing data quality.

2. Method

To investigate the research potential of data from the municipal EHR an explanatory sequential mixed-method case study was chosen [10,11]. Fig. 1 illustrates the methodological approach. The reporting of the study complies with the Good Reporting of A Mixed Methods Study (GRAMMS) [12].

Step 1: The clinical data of low back pain (LBP) patients is documented in the therapeutic record of the EHR, at a municipal rehabilitation unit located in Northern Denmark. We identified and analyzed retrospectively, data from 172 LBP patients (from 1.1.2015-31.12.2015). In order to investigate the data quality, data from each patient was manually searched for outcome measures for pain and physical function, two outcome measures recommended by the IMMPACT guidelines [13,14]. In most municipal EHR data measures of pain was, when reported, documented using Visual Analog Scale (VAS) or Numeric Rating Scale (NRS) and physical function was, when reported, documented using Roland Morris Disability Questionnaire or other e.g. subjective therapeutic evaluation [13,14]. Numerical data for changes in pain or physical function were categorized into ‘better’, ‘worse’, ‘no difference’, ‘data missing’ prior to statistical analysis.

Step 2: The results from the quantitative analysis left a black box regarding the effect of rehabilitation. Data was missing on outcome for either pain (n=86), physical function (n=89) or both (n=122). To explore this, five randomly selected municipal EHR were subject for a direct content analysis of the unstructured clinical notes. The content analysis was directed by Strong, Lee and Wang’s (1997) definition of high quality data as being conform, accurate, complete and valid [5]. The analysis consisted of systematically classifying, coding and identifying themes or patterns in the municipal EHR, in order to deepen the understanding of data presentation and quality in the municipal EHR, and explore the challenges on using these data for research and quality assessment [10,11,15].
Step 3: The results and findings from step 1 and 2 were analyzed and merged into a final interpretation. The merging lead to further investigation of potential causality between documentation methodology (i.e., choices) and the data quality in the municipal EHR.

Generally, the data documented in the municipal EHR contain information on examination, assessment, and status of rehabilitation upon discharge. The data was analyzed on the start- and end note of the municipal EHR for both step 1 (quantitative) and step 2 (qualitative).

3. Results

3.1. Quantitative results

Outcome measures of pain and physical function were documented and recognizable within the categories 'better', 'worse' or 'no difference' in 50% and 48% of the municipal EHR, respectively. In 29 % of the municipal EHR outcome measures both pain and physical function was documented at recognizable.

Valid outcome measures were documented in the start note and end note of the EHR for pain (42% and 13%), and physical function (1% and 0%), respectively – see Table 1.

<table>
<thead>
<tr>
<th>EHR (n=172)</th>
<th>VAS/NRS; documented</th>
<th>VAS/NRS; not documented</th>
<th>RMDQ; documented</th>
<th>RMDQ; not documented</th>
<th>VAS/NRS and RMDQ</th>
</tr>
</thead>
<tbody>
<tr>
<td>Start note (%)</td>
<td>42</td>
<td>55</td>
<td>1</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>End note (%)</td>
<td>13</td>
<td>77</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>

Notes: Pain: Visual Analog Scale (VAS) or Narrative Rating Scale (NRS);
Physical function: Roland Morris disability questionnaire (RMDQ)

3.2. Qualitative findings

The directed content analysis searched for indicators on data’s conformity, accuracy, completeness, and validity (data quality) in the municipal EHR. The analysis revealed imprecise and inadequate use of outcome measures matching evidence in the field and inconsistent, nonsystematic use of valid and reliable outcome measures, which challenges group comparison of effect (Table 2).

<table>
<thead>
<tr>
<th>Table 2 Themes from municipal EHR regarding data presentation and quality.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Imprecise and inadequate use of outcome measures for pain and physical function do not match the evidence in the field.</td>
</tr>
<tr>
<td>Inconsistent and nonsystematic use of outcome measures.</td>
</tr>
<tr>
<td>Inconsistent use of valid and reliable outcome measures.</td>
</tr>
<tr>
<td>Inconsistent documentation challenges comparison of data from municipal EHR on a group level.</td>
</tr>
</tbody>
</table>
4. Discussion

Outcome measures, as recommended by the IMMPACT guidelines, were to some extent documented for pain and physical function, however the use of valid measuring methods was inconsistent and data was imprecisely reported. Outcome measures on pain and physical function were therefore inconclusive in approximately half the cases. Compared by IMMPACT guidelines, data was not adequately collected or documented. The documentation outcome measures on pain and physical function were inconsistent, invalid and nonsystematic, e.g. effect on pain was reported in the municipal EHR using VAS or NRS in 42% of the rehabilitation start notes but same outcome measure was only reported in 13% of the end notes. The content analysis of the five municipal EHR demonstrated that the therapist in general deviate from the reporting standards of the IMMPACT-guidelines, thereby creating a barrier towards reusing clinical data for research purposes [13,14]. The observed data quality was considered poor as data was neither conform nor accurately, completely and validly documented, thus compromising group comparisons and further data analyses. Other studies have shown similar challenges; COUMT might make sense in settings where data quality is high, however poor data quality compromises that vision [4,16,17].

If data is to be reused for quality assessment or research purposes, outcome measures of treatment must be performed and documented accurately, adequately, consistently and systematically using valid and reliable measurement methods that matches applicable clinical guidelines for rehabilitation [4]. To produce high quality data suitable for research and quality assessment both therapist, management, and politicians must understand the complexity of the COUMT paradigm. These differences in interest must be defined for all stakeholders involved in municipal EHR documentation to insure a data quality corresponding to research standards.

Data quality seems equivalent to the relevance data has for the end-user, meaning that data quality from a therapeutic point of view might differ from data quality from a quality assessment or research perspective. Even though data in the municipal EHR might be valuable for individual therapists, data was inadequate from a research perspective. For the COUMT paradigm to be applicable in a municipal EHR (secondary sector), there is need for a thorough implementation process ensuring that documentation criteria and guidelines are understood, accepted and met [18]. However, prior to such an implementation, a clear definition of data quality for the individual therapeutic specialty must lead to clear documentation guidelines. The findings of this study underpin that documentation guidelines should take into consideration the complexity of the COUMT paradigm and insure that municipal EHR contains valid and accurate data that is relevant to the end user such as researchers [4,7]. The municipal EHR and documentation guidelines should encourage and support documentation of conform and accurate data using relevant, valid and reliable measuring methods.

5. Conclusion

The objective of this study was to investigate the research potential of low back pain patients’ municipal electronic healthcare records. In conclusion, the data were non-conform, inaccurate, incomplete and invalid. The poor data quality is a potential barrier for introducing the COUMT paradigm, which is a prerequisite in reusing clinical data for quality assessment and research purposes.
References


