Medical Informatics and the Internet in Medicine
Publication details, including instructions for authors and subscription information:
http://www.tandfonline.com/loi/imif19

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Published online: 18 Apr 2015.

To cite this article: Renske K. Los, Astrid M. Van Ginneken, Jolt Roukema, Henriette A. Moll & Johan Van Der Lei (2005) Why are structured data different? Relating differences in data representation to the rationale of OpenSDE, Medical Informatics and the Internet in Medicine, 30:4, 267-276

To link to this article: http://dx.doi.org/10.1080/14639230500367563

Medical Informatics and the Internet in Medicine
December 2005; 30(4): 267–276

Why are structured data different? Relating differences in data representation to the rationale of OpenSDE

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(Received April 2005; accepted September 2005)

Abstract
OpenSDE is an application that supports clinicians with structured recording of narrative patient data to enable use of data in both clinical practice and research. OpenSDE is based on a rationale and requirements for structured data entry. In this study, we analyse the impact of the rationale and the requirements on data representation using OpenSDE. Three paediatricians transcribed 20 paper patient records using OpenSDE. The transcribed records were compared; the findings that were the same in content but differed in representation (e.g. recorded as free text instead of in a structured manner) were categorized in one of three categories of difference in representation. The transcribed records contained 1764 findings in total. The medical content of 302 of these findings was represented differently by at least one clinician and was thus included in this study. In OpenSDE, clinicians are free to determine the degree of detail at which patient data are described. This flexibility accounts for 87% of the differences in data representation. Thirteen per cent of the differences are due to clinicians interpreting and translating phrases from the source text and transcribing these to (different) concepts in OpenSDE. The differences in data representation largely result from initial design decisions for OpenSDE.

Keywords: *Structured data entry, information storage and retrieval, medical records*

1. Introduction

> It can readily be seen that all narrative data presently in the medical record can be structured, and [...] entered through series of displays, guaranteeing a thoroughness, retrievability, efficiency and economy important to the scientific analysis of a type of datum that has hitherto been handled in a very unrigorous manner.—Lawrence L. Weed, 1968 [1].

Electronic patient records (EPRs) are associated with many potential benefits such as availability of patient data for decision support, quality assessment, or clinical research [2,3].

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ISSN 1463-9238 print/ISSN 1464-5238 online © 2005 Taylor & Francis
DOI: 10.1080/14639230500367563

However, to benefit from such advantages, data must be represented in a structured format [4,5]. Structured Data Entry (SDE) is a method by which clinicians record patient data directly in a structured format. SDE offers predefined fields for data entry. As early as 1968, the potential for SDE, as well as subsequent use of the collected data for analysis purposes, was recognized by Weed [1]. However, to date, SDE remains challenging to apply for medical narratives (especially patient history and physical examination), as these data vary per domain, per patient, and over time [6–9].

Since the early 1990s, our philosophy regarding SDE has been that free-text narratives should be minimized in favour of clinically relevant structured data for multiple purposes. Our rationale for SDE is based on data entry by clinicians. The challenge is to approach the expressive power of free text while keeping SDE acceptable for clinicians.

In OpenSDE, our current SDE application, we respected the clinicians' need for flexibility and expressiveness, i.e. data entry with certain degrees of freedom, to describe findings. Freedom in data entry, however, implies that the same data may be recorded differently by different clinicians [10]. For purposes such as research and decision support, on the other hand, a structured, uniform representation of the same data set is essential. The question that thus arises is: what is the impact of the expressiveness and flexibility offered to support SDE, on the uniformity of the data set?

In this paper, we discuss differences in data representation that are a result of the design of OpenSDE, and propose changes in the data-entry paradigm to increase the uniformity in data representation.

2. Research focus

In view of our rationale for SDE, Moorman et al. formulated requirements that should be met to make structured data entry acceptable for clinicians [11]. Three of these requirements are pivotal for OpenSDE [12,13]. First of all, SDE should provide sufficient *expressive* power to describe clinically relevant details; this expressiveness must be offered in the form of predefined terms (which by definition limits expressiveness). Second, SDE has to be *flexible* to offer the clinician the freedom to determine the order and degree of detail of what he describes; enforcing detail or order in data entry does not enhance acceptability. The third crucial requirement is that data should be presented in a *predictable* order so that, when browsing through the data, clinicians know where to expect specific information.

To analyse the impact of expressiveness, flexibility, and a predictable order on data representation, we performed a study in which three paediatricians transcribed patient data from a common data source. Research has shown that when transcribing findings from the same handwritten paper source into a flexible structured electronic record, differences between the three transcribed records are inherent [14,15]. Horwitz and Yu report three different data-recording errors: conflicting data in the source text, information not transcribed, and transcription errors [14,16]. In our study, we distinguish two types of differences: first, there are differences in data content, and second, there are differences in data representation. Differences in data content include errors such as those described by Horwitz and Yu. We are, however, particularly interested in patient data that differ in representation, for example, a finding is recorded (partly) as free text instead of in a structured manner. This type of difference implies that the participating clinicians recorded findings representing the same medical content but structured the patient data differently. Even in OpenSDE, we cannot guarantee that the same content is represented in the same manner. In OpenSDE, findings that are transcribed differently can vary both in level of structure and place in the database where the findings were recorded. The object of this study is to identify categories of differences between representations of the same patient data. Based on these categories, we can propose changes that limit differences in data representation.

3. Materials

3.1. OpenSDE

OpenSDE supports clinicians with the structured recording of medical narratives [17 – 19]. The pivot of OpenSDE is the domain model: a tree of hierarchically ordered medical concepts. The tree is domain-specific and holds the concepts necessary to describe findings in a particular domain of medicine. Domain models are created by domain experts using a specifically designed tool [18]. The use of the tool as such is not difficult; the difficulty lies in the actual modelling. There are two main issues that make modelling complex. First, the modellers need to decide to what level of detail concepts should be modelled in the tree [20]. Second, one needs to minimize the number of possibilities in which the same data can be recorded in different manners.

In a domain model, the path from the top of the tree to a particular concept represents the context of that concept. A typical domain model will start with very broad concepts which become more specific as the tree branches. Each concept in the tree is associated with an application generated entry form (which can be customized using an integrated form editor). Using this entry form, clinicians can describe a particular finding, such as a new mole, in more detail. Details may include whether the finding applies or not (e.g. a mole is present), the date of the mole's discovery (temporal value), the size (numerical value), and the colour (categorical value) of the mole. It is also possible to describe findings more than once in the context of progression over time (e.g. changes in size/colour), different circumstances (e.g. before/after sunbathing), or multiple occurrences (more than one mole).

Like many systems designed for recording heterogeneous and evolving data sets [21 – 24], OpenSDE relies on a generic data model for data storage [12]. Figure 1 presents a screen capture of OpenSDE.

OpenSDE reflects the three essential requirements for SDE. The hierarchical nature of the domain model allows findings to be specified at varying levels of granularity to accommodate the desired degree of structured expressiveness (first SDE requirement). The hierarchy presents concepts for data entry in a predictable order (third SDE requirement). Flexibility, the second SDE requirement, is supported in two ways. First, OpenSDE does not enforce a specific order or level of detail at which findings must be described. Second, OpenSDE does not enforce structure; recording data as free text is always possible (at every concept in the tree) for particular details not covered by the content of the domain model.

Prior to this study, experienced OpenSDE users recorded data of over 100 paediatric paper records in OpenSDE to evaluate the ordering and coverage of the paediatric domain model. The model was then altered to improve both ordering and coverage, as well as to facilitate data entry [25].

4. Methods

4.1. Data entry from a common data source

Three paediatricians working at our hospital's paediatric outpatient department followed a standardized course on the use of OpenSDE in general paediatrics. We randomly selected 20 handwritten paper patient records created for first-contact patients at the paediatric outpatient

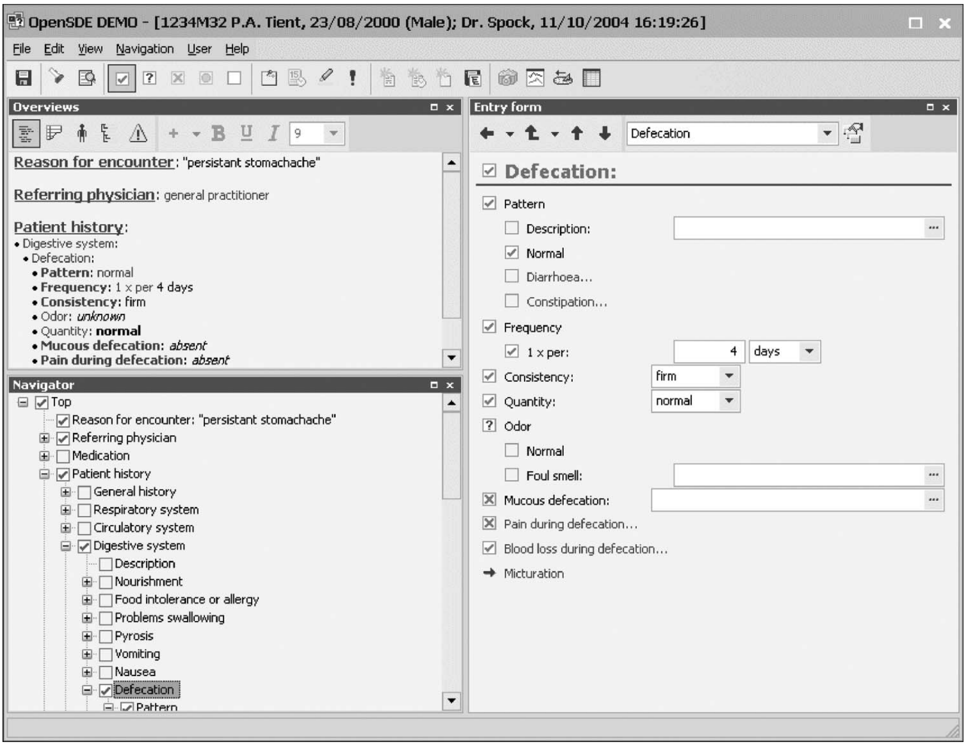


Figure 1. Screen capture of the OpenSDE data entry application. The top left of the screen shows an overview of the data recorded for the patient in the current session. The bottom left shows the domain model tree with medical concepts. On the right is the form on which data are entered. The form is associated with the selected node, in this case 'defecation'. At the bottom of the defecation form, the term 'Micturation' is preceded by an arrow which indicates that micturation is modelled in detail elsewhere. Clicking on the term will present the form used to describe micturation.

department. These patients were not treated by any one of the three paediatricians involved in this study. Each paediatrician transcribed the 20 paper records in OpenSDE, resulting in a total data set of 60 transcribed records. The paediatricians were informed about the goal of the study and knew that the transcribed records would be analysed.

4.2. *Non-uniformly transcribed patient data*

Our analysis consisted of two steps. The first step involved manually analysing the medical content and data representation in the transcribed records. Per patient record, we explored whether all three clinicians recorded the same medical content identically, differently, or whether there was a difference in data content (e.g. errors, or missing data). If the same medical content was present in all three transcribed records, but represented differently in at least one of the transcribed records, the corresponding findings were included in this study. Patient data represented in the same manner by all three clinicians or transcribed findings that differed in data content were excluded from the study.

The second step involved identifying categories of differences in data representation. We identified three categories of differences. Consequently, we classified each finding in one of the categories as described below.

If the same medical content was represented (partly) as free text at a different node in the same path, i.e. in more or less detail, the finding was classified as a difference due to flexibility in representation ('Flexibility' in Results Table I). Figure 2 presents an example where stomach ache is described in a structured manner by recording details such as onset, localization, and duration at the specific concepts in the tree, and also shows how these details can be described as free text for the concept 'stomach ache'.

If the finding did not belong to the first category, we checked if the patient data were represented in a different path in the tree. In some cases a domain model offers multiple entry options to describe the same medical content. If a finding is represented at such a semantically similar concept, we classified the finding as a difference due to semantic similarity ('Semantic similarity' in Results Table I). Nutrition is such an example. Eating habits can be described by normal, increased, or decreased appetite and are relevant in the context of the digestive system. Nutritional intake, on the other hand, was modelled separate from the digestive system. As eating habits and intake are closely related, modelling these concepts apart from each other, at different places in the tree is not practical for data entry. Hence, some users record all related patient data at only one of these concepts: e.g. eating habits are represented as free text at the nutritional intake concept.

The last category of difference that we identified constitutes findings that involve a judgement or an interpretation as the phrases used in the paper record cannot directly be translated (or mapped) to the same concepts in the domain model ('Mapping' in Results Table I). For example, the paper record may contain the phrase 'lively bowel sounds'. If the entry options in OpenSDE only include bowel sounds normal or abnormal, translating 'lively bowel sounds' will require interpreting whether lively bowel sounds are normal or abnormal. Some clinicians will choose to interpret these bowel sounds as 'normal bowel sounds', whereas another may choose to record 'lively bowel sounds' as free text.

Per finding meeting the inclusion criteria, we also established the part of the patient record to which it belonged (patient history or physical examination) and whether the finding was normal (e.g. 'no cardiac murmur') or abnormal (e.g. 'constipation').

5. Results

The transcribed records contained a total of 1764 findings; the medical content of 302 of these findings (17% of all findings) was represented differently by the three clinicians. These

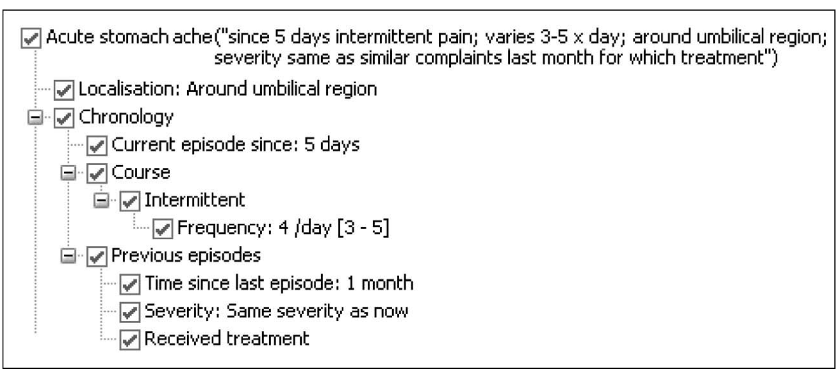


Figure 2. Example of structured and free-text representation of patient data. The description of acute stomach ache is represented both in a structured format in the tree and as free text behind the node 'acute stomach ache'.

302 findings are the findings of interest for this study. In Table I, we present the findings per category of difference, and we divide the findings into patient history or physical examination findings. The table shows that most findings are patient history findings. Patient history findings are predominantly abnormal findings, whereas physical examination findings are mostly normal.

Table I. Findings represented differently ordered per category of difference.

	Patient history		Physical examination		
Category	Normal	Abnormal	Normal	Abnormal	All findings
Flexibility	89 (29.5%)	128 (42.4%)	30 (9.9%)	5 (1.7%)	252 (83.4%)
Semantic similarity	3 (1%)	9 (3%)			12 (4%)
Mapping	4 (1.3%)	3 (1%)	28 (9.3%)	3 (1%)	38 (12.6%)
All findings	96 (31.8%)	140 (46.4%)	58 (19.2%)	8 (2.6%)	302 (100%)

This table presents the findings structured differently by the three clinicians. A total of 302 findings were represented differently. Per category of difference, the findings are split into patient history or physical examination findings, and consequently subdivided into normal or abnormal findings. The percentage behind the numbers corresponds to the percentage of the total number of findings.

Of all 302 findings, the majority (83%) constitutes ‘flexibility’ differences, 13% involves ‘mapping’, and 4% was classified as differences due to ‘semantic similarity’.

Differences due to flexibility occur most often in the abnormal patient history findings, as opposed to the physical examination where the clinicians chose to represent the normal findings at different places in a path.

As shown in Table I, differences due to mapping are mainly normal physical examination findings.

6. Discussion

The goal of OpenSDE is that clinicians can record patient data in a format in which data are usable for multiple purposes. One of the main challenges for OpenSDE was to approach the expressive power and flexibility of free text, while keeping SDE acceptable for clinicians. To meet this challenge, Moorman et al. [11] formulated requirements for SDE.

In this study, we identify three categories of differences in data representation. In hindsight, these categories result from initial design decisions and more specifically from the three requirements of supporting expressiveness, flexibility, and a predictable order for data entry. In this discussion, we will first focus on the consequences of our design decisions for SDE on the representation of data in the context of data extraction. Consequently, we propose alterations that aim to reduce the differences in data representation while upholding the underlying design philosophy.

6.1. Effect of requirements for SDE on data representation

6.1.1. ‘Flexibility’ and flexibility (second requirement for SDE)

Of all findings represented differently in the transcribed records, a majority of 83% was categorized as different due to ‘flexibility’.

To support flexibility in SDE, OpenSDE first does not enforce a specific detail-level or structure in which findings must be described, and second enables the use of free text where needed (second SDE requirement). This design has led to a very flexible use of OpenSDE; our results illustrate that clinicians use free text to represent findings that can be structured. Clinicians also record the same data as free text at different places in the tree. Flexibility is an advantage for data entry, but it is a hurdle for data look-up and extraction, as data can be recorded at more than one place (making data representation less predictable). The dilemma we now face is: do we uphold our rationale and retain this flexibility in data entry, or do we compromise this flexibility in order to increase uniformity of the data set?

6.1.2. 'Mapping' and expressive power (first requirement for SDE)

Almost 13% of the findings represented differently were categorized as differences due to 'mapping'.

Although predefined terms imply limited expressiveness, OpenSDE aims to provide the clinician with sufficient expressive power to describe clinically relevant details. A domain model is, however, limited in scope and may not always contain the exact terms that clinicians would like to use, or may not present terms in the exact context in which clinicians would preferably use the terms[1]. Transcribing findings thus involves interpreting the finding in the paper record (for which the clinicians use their own reference [26]) and then translating or mapping the finding to those concepts in OpenSDE that best match the description of the finding in the paper record. Almost 13% of the findings were categorized as such mapping differences.

Analysis of these 38 predominantly physical examination findings revealed that for 30 of these findings, the concept 'normal' or 'abnormal' was modelled in the finding's path. Although the domain model allows for recording of expressiveness (including judgements), the predefined order of the terms has an effect on how the data are represented. In cases where judgements are recorded, expressiveness is often incorrectly modelled (observations are often modelled as branching nodes of concepts representing judgements). The domain model forces the user to judge whether particular findings are normal or abnormal. The clinical meaning of terms such as 'normal' is, however, subject to interpretation of the clinician who records the findings and the clinicians or researchers that consult the findings [27]. The example of the lively bowel sounds mentioned previously represents a situation that can be normal in one scenario and abnormal in another. Nevertheless, the frequent use of such subjective terms, both in the paediatric domain model and in the paper records, indicates that clinicians apparently have a need to express that, according to their judgement, particular findings are 'normal'. The question now is: how should OpenSDE support expressive recording of observations and interpretations?

6.1.3. 'Semantic similarity' and predictable order (third requirement for SDE)

The last category of difference involves findings classified in the 'semantic similarity' category. A total of 4% of findings represented differently are recorded at more than one branch in the tree due to duplication of concepts or the presence of semantically very similar concepts in the domain model.

OpenSDE has functionality to handle patient data that are relevant to describe in more than one context. The functionality consists of a reference mechanism within a domain model to accommodate access to concepts via more than one context, while the data are only represented in one unique way (i.e. in one predictable order: third SDE requirement).

6.2. Future choices

The results of this study illustrate that providing freedom in data entry will lead to use of this freedom during data entry. This freedom, therefore, is in conflict with uniform data representation. Our initial goal was that clinicians directly record data in a structured manner suitable for multiple purposes. The question is thus: should we retain focus on facilitating data entry in order to obtain as many clinicians using the application as possible, and sacrifice the uniformity of the collected data, or should the uniformity of the data set be our priority and should we sacrifice the freedom in data entry? The first option may lead to a more widespread use of OpenSDE but is less effective in promoting data collection suitable for other purposes such as (retrospective) research or quality assessment. The second option, on the other hand, may be preferable for additional benefits of structured data, but if clinicians refuse to use the application, there are no data from which to benefit. In essence, the clinicians are pivotal in the data-collection process, but must we go to great lengths to accommodate needs and preferences for data entry, if this means that potential use of data becomes limited [28]?

In an attempt to reduce the differences in data recording with OpenSDE, we propose four measures that should improve the uniformity of the data set, while minimizing the impact on flexibility and expressiveness. The proposed measures include:

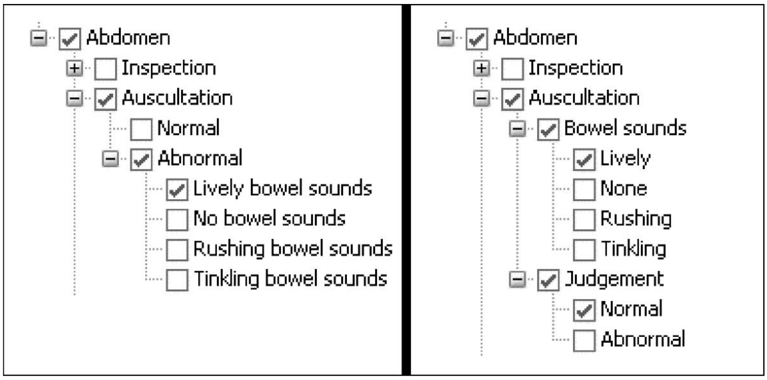
1. limiting the use of free text;
2. explicitly separating interpretations from judgements;
3. facilitating uniform data entry by using templates and checklists;
4. developing modelling guidelines.

Our first proposal is to limit the use of free text. When the aim is to structure data for research purposes, free text is ideally limited, as free text complicates research on the data. Nevertheless, for patient care, free text cannot be eliminated [29]. Therefore, we propose to limit the use of free text to predefined nodes in the tree. If a clinician chooses to record free text at any node in the path, they will be redirected to the node at which it is allowed. This construction does not sacrifice expressiveness, as free text can still be added and offers the advantage that when consulting the data, free text is limited to predictable places. This may not reduce the use of free text, but it will reduce the chance of overlooking a finding recorded as free text, as free text cannot be scattered anywhere in the tree.

Our second proposal is to separate specific judgemental concepts about observations from the observations themselves. Judgements such as ‘normal’ are ideally separated from descriptive concepts such as ‘lively bowel sounds’ in the domain models. By separation, we mean not to place such concepts in the same path. Figure 3 illustrates how not to model judgemental concepts (Figure 3a) and how we propose to model judgemental concepts (Figure 3b).

For those situations in which more than one finding is normal, e.g. the auscultation of the heart is normal, we suggest the use of customized (user-specific) templates for particular sets of findings. A template ‘auscultation heart normal’ will consist of findings such as first and second heart sounds present, with no murmurs. This template will mean the same across all patients seen by a particular clinician. Templates have obvious advantages and disadvantages, and their use is not without risk. Templates may lead to documentation of observations that were not performed. On the other hand, not using templates may lead to findings inadvertently being omitted from the patient record [29]. Using templates has two practical advantages: it can speed up data entry as well as increase the consistency of the entered data.

In those situations where structured recording of particular findings is essential (e.g. for vital patient characteristics or prospective research purposes), the use of data checklists to remind users to record data about particular findings is recommended. Checklists are an optional function available in OpenSDE.



(a) **(b)**

Figure 3. Extract of the domain model used for paediatrics. In (a), modelling findings in the same path as judgemental concepts such as abnormal can lead to erroneous data. (b) illustrates a different way to model judgement concepts, namely not in the same path but parallel to the findings. This allows for structured representation of the (objective) finding, as well as the addition of a judgement.

A last proposal is to develop modelling guidelines. The guidelines should emphasize recommendations 2 and 3 as well as promote the use of referencing to avoid duplication of semantically similar descriptions. The modelling guidelines should pursue a balance between representing those concepts that may be relevant to describe in particular contexts and representing concepts in such a manner that uniformity in data representation is optimized.

We expect that these alterations will improve the uniformity of the data set, while impact on flexibility and expressiveness for data entry is minimal [27], thus upholding the rationale and requirements. However, if there is anything that we learned from this study, it is that the impact of decisions is not fully predictable, and repercussion is often unforeseen.

Note

1. A similar situation can occur when clinicians enter findings directly in OpenSDE instead of transcribing findings from a paper record.

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