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# The Need for Standardised Documents in Continuity of Care: Results of Standardising the eNursing Summary

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#### Abstract

Continuity of care is a concept that is defined as the uninterrupted and coordinated care provided to a patient and that includes an informational dimension which describes the information exchange between the parties involved. In nursing, the nursing summary is the main instrument to ensure informational continuity of care. The aim of this paper is to present an HL7 Clinical Document Architecture based document standard for the eNursing Summary and to discuss the need for harmonizing these results at international level. The eNursing Summary proposed in this paper was developed on the basis of several internationally accepted concepts, primarily the nursing process, the ISO 18104 Reference Terminology Model for Nursing and various data sets. The standardisation process embraced several phases of involving nursing experts for validating its structure and content. It was finally evaluated by a network of 100 healthcare organizations. We argue that the eNursing Summary is a good starting point for standardising nursing discharge and transfer documents on a global level. However, further work is needed to bring together the different national and international strands in standardisation. .

# Keywords:

Continuity of care, Nursing summary, HL7 Clinical Document Architecture, ISO 18104 Reference Terminology Model for Nursing

# Introduction

Decreased length of stay in hospitals, early discharges from hospitals and the proliferation of fragmented healthcare services have contributed to a renewed interest in continuity of care as a concept for ensuring quality of care. Defined as the delivery of care to a patient by care providers "in an uninterrupted and coordinated manner" [1], it aims at bridging gaps between settings, institutions, healthcare professionals and between shifts. The non-attendance to continued care may lead to severe hazards for the patient such as adverse drug events [2]

and is a clear risk factor in patient safety [3]. Continuity of care is a multi-dimensional concept which comprises of different levels referring to information, management, relationship and contact issues [4]. The informational dimension typically addresses the need for consistent, complete, up-to-date and timely patient information to be transferred between healthcare institutions or healthcare professionals in charge of providing care for the patients. New studies give insight into how technology and electronic health records (EHR) in particular can support a seamless flow of information within [5] and across institutions [6] without compromising privacy [7]. Sharing data between healthcare providers by means of an EHR is one approach of transmitting relevant information. In addition, messages can be exchanged between the health information systems concerned [8] or summary documents can be sent via electronic networks. Finally, summary documents can be also made available through shared document repositories with IHE XDS [9].

Nurses have had a long-standing interest in implementing continuity of care in their daily work [10], in particular in their role as discharge managers, case managers and community nurses. Their information needs have been clearly stated early on [11]. Only with the increasing prevalence of electronic nursing information systems in healthcare institutions [12] electronic exchange of nursing information across institutions becomes possible. National eHealth initiatives in many industrialized countries in addition have given momentum for including nursing information in the electronic healthcare information chain [13, 14]. Despite the definite need for an electronic nursing summary in many countries, national standards are rare (e.g. there is one in Finland [15]) and an internationally coordinated approach for standardising the nursing summary does not yet formally exist.

The aim of this paper is therefore to present the results of a standardisation process for the electronic nursing summary in Germany and hereby to stimulate the corresponding discussion at international level.

## **Materials and Methods**

# Defining the nursing summary and its core elements

By nursing summary we mean a document which summarizes all major health events of a given patient from the nursing perspective of the discharging or transferring institution. It makes use of the wealth of information from the maximum data set (nursing record) and is distinct from the nursing minimum data set. It is less aggregated than the minimum data set and focuses on the continued care of an individual patient.

A proposal for core elements of the nursing summary was derived from relevant standards, in particular the Continuity of Care Record [16], the Swiss "NURSING data" data sets [17], the Reference Terminology Model for Nursing [18] and the definition of HL7 nursing meta-observations [19]. The proposal also drew from our own previous work [20, 21]. It was further refined by members of the "Continuity of Care Network in the Osnabrück Region" (www.netzwerk-os.de) who established an eNursing Summary working group in 2006. The Network consists of healthcare institutions which represent the primary, secondary and tertiary healthcare sector and thus could provide a comprehensive overview of the information needs across the care continuum. Consensus was reached by means of a nominal group process. In 2007 and 2008 the results were presented in workshops at regional, national and multinational conferences (e.g. European Nursing Informatics ENI 2008 in Münster, Germany). Suggestions for modifications, e.g. biographical patient information, were incorporated in an updated version of the nursing summary. The developments took place under the auspices of the German Council of Nurses.

# Building an information model of the nursing summary

HL7's Clinical Document Architecture (CDA) Release 2 [22] and the corresponding Reference Information Model (RIM) were utilized to structure the relevant data into a header and body section and to model the information. The document header was adopted to a great extent from the German discharge letter [23]. HL7 CDA classes, elements, data types and attributes were specified and modelled with the help of HL7-RIMDesigner in Microsoft Visio and RoseTree. LOINC-codes were used for coding the document sections. XML instances were created, drawn from the model and populated with example data.

# Standardising and evaluating the nursing summary

The eNursing Summary undergoes the formal standardisation process of the HL7 German User Group in autumn 2009 and will subsequently be made available via its website (www.hl7.de). In parallel, contacts were established in 2009 to the Nursing Network Heilbronn, Germany, a regional network composed of 100 nursing care institutions, for evaluating the eNursing Summary data set and its structure by cross-mapping them to their paper-based nursing discharge letter. This discharge letter is the result of an internal standardisation process among the member institutions which all use it for exchanging patient information. The cross-mapping was performed by four

experts (two of the authors [UH, DF], the chairman of the Heilbronn Network and a nursing expert from a software company).

## Results

# Information model of the eNursing Summary

The HL7 CDA based eNursing Summary is a structured clinical document. In contrast to its header, its body is specific to nursing. It has been broken down into the following sections (fig. 1): a) nursing process, b) social information, c) reference to legal documents, d) home care status and e) medical information. The "NursingProcess" section is the central part of the eNursing Summary (fig. 2). Nurses use the nursing process as fundamental concept to assess, identify nursing diagnoses, determine expected outcome plans, implement and evaluate patient responses to provide effective care [24]. The section is subdivided into the concepts Nursing Score, Nursing Diagnosis, Nursing Goal, Nursing Procedure and Nursing Outcome. Nursing Score summarizes the results of assessment scales used in the diagnostic process. The nursing diagnoses are described in Nursing Diagnosis which is further specified by the subconcepts Etiology, Symptoms and Resources. Nursing Procedure is always triggered by other nursing concepts, such as Nursing Diagnosis, and can be followed by a Nursing Outcome. Groups of scores, nursing diagnoses, nursing goals, nursing procedures and nursing outcomes may be clustered by themes, such as the activities of daily living (ADL), or by userdefined themes. The use of ADLs is not mandatory, neither is any other taxonomy because any predefined scheme would imply a specific nursing theory as default. Furthermore, studies showed a considerable amount of disagreement among specialty practice groups on what information was critically important for continuity of care [11]. We therefore favoured a more formal approach, i.e. using the nursing process as guiding structure, and left clusters of themes open for definition by user groups.

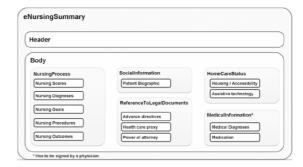


Figure 1- Structure of the eNursing Summary Body

Also at the level of entries the "NursingProcess" section does not propose any particular nursing terminology but is open to different controlled vocabularies. The eNursing Summary, however, recommends at least regional specifications of the terminologies preferred by the healthcare providers in that area. The "SocialInformation" section covers a short non-structured note on the patient's or client's biography (CDA level 1 and 2). The "ReferenceToLegalDocuments" section allows legal and official documents to be referenced, i.e. meta-data of these documents to be communicated, such as date of issue, the depository and contact persons.

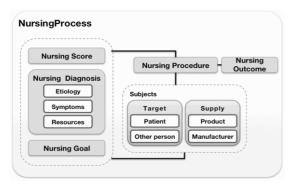


Figure 2- Concepts of the NursingProcess

These two sections were added pursuant to special requests from institutions that are in charge of the care of the elderly, in particular of dementia patients, e.g. nursing homes, geriatric clinics, geriatric hospital departments and ambulatory care services, and from psychiatric care institutions. The "HomeCareStatus" section describes the private and social environment where the patient lives, constructional issues of the home and the assistive technology that is available. Rehabilitation centers, home care providers (nurse specialists) and ambulatory nursing services particularly benefit from information of this section but also therapists in hospitals and other organisations. Information for the sections "SocialInformation", "ReferenceToLegal-Documents" and "HomeCare-Status" may be provided either by nurses or social workers depending on who is in charge of social care issues. Finally, the section "MedicalInformation" is a data container for medication data and medical diagnoses. It is copied from the medical summary or provided by physicians who are the authors and the signatories of this section.

The information model was checked for consistency and mapped into the proper CDA structures and corresponding domain message information models. The eNursing Summary concepts were represented by the use of specific terminology in the generic CDA classes.

# **Evaluation of the eNursing Summary**

The results of the cross-mapping showed that all data fields of the Heilbronn nursing discharge letter could be translated into the eNursing Summary standard. The discharge form, however, differed from the standard with regard to the relations between diagnoses and interventions. Whereas the standard requires interventions to be linked to the cause of the intervention, typically the nursing diagnosis, the Heilbronn discharge letter consisted of a loose enumeration of unrelated problems and interventions. Furthermore, it did not specify any standardised nursing terminology to be used but rather preferred free text fields.

Both can be represented in CDA documents and thus also in the eNursing Summary.

#### Discussion

# The multidisciplinary nature of the nursing summary

The eNursing Summary is a communication instrument in ICT supported care delivery scenarios (fig. 3). Its main purpose is to warrant informational continuity of care across the spectrum of settings. The results of the standardisation process demonstrate that the nursing summary can be structured in a general way if the nursing process is utilized as the major guideline. Only then it is independent of the setting and the nursing specialty. When used in the context of the nursing summary the nursing process refers to critically important information and the patient status at discharge or transfer. It therefore does not contain the nursing assessment which is again carried out by the nurses who continue the care. In addition to the nursing process, the eNursing Summary also consists of medical, social and legal information that is needed by the institution or healthcare professional in charge of the follow-up care. As figure 3 shows the eNursing Summary may also contain information that is shared between nurses and therapists, e.g. information concerning the mobilization of a stroke patient. This fact hints at the interdisciplinary nature of the nursing summary and the role of nurses as generalists in the healthcare arena. It also raises the question of whether there is the need for a multi-professional summary to guarantee informational continuity of care. There is indeed critical overlap of information, notably in the medical area. There have been aivid discussions during the definition phase of the nursing summary on the need to know the medication and the medical diagnoses of a patient. This requirement can be met by two ways: either by referring loosely to the medical summary which would be (hopefully) sent in parallel or by copying these parts into the eNursing Summary. We finally decided for the latter solution in order to closely couple these pieces of information that need to be available at the same time for continuing the care. In the long run, the goal, however, should be to establish a multi-professional summary document. We made a first step towards this direction when adopting the content of the header from the medical summary.

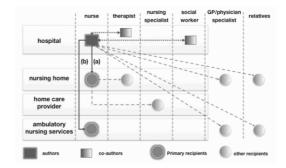


Figure 3- Continuity of care scenario; legend: patient discharged to (a) home, (b) nursing home

## The need for harmonization at international level

There are several reasons that speak in favour of seeking to standardise the nursing summary at international level. First of all, the nursing process, which constitutes the backbone of the eNursing Summary, is an internationally accepted concept that is used - with variations - in many countries [25]. The second major contributor to the eNursing Summary is the Reference Terminology Model for Nursing [18], which is an ISO standard and ensures a common understanding of what is the essence of a nursing diagnose and a nursing intervention. Both approaches, the nursing process and the ISO standard, give the eNursing Summary a formal structure that makes it independent of a structure defined by content, e.g. by ADLs. This is paramount in an international context because the content may vary from country to country according to the culture and to the different task profiles of the nurses in different countries. The eNursing Summary allows so called themes to be included on an optional basis to make it flexible to the various demands and to enhance its readability.

There is also a need for standardising discharge and transfer documents from a European perspective. The European eHealth Action Plan [26] and the proposed European Directive on cross-border healthcare [27], both call for standardised procedures each from their own point of view. The eHealth Action Plan [26] addresses the need for developing interoperable health information systems, in particular electronic health record systems, as one of the most urgent challenges to be tackled. Interoperability is inseparably linked with the availability of accepted standards, also in nursing. The proposed EU Directive on cross-border healthcare [27] states that "ensuring continuity of cross-border healthcare depends on timely transfer of data concerning patient's health".

Finally, there is a growing interest among the health-IT vendors in internationally accepted standards as clinical health-IT-solutions are increasingly marketed on a global level, e.g. by international companies..

#### Need for action

Due to the critical importance of the electronic nursing summary in eHealth scenarios activities of international bodies for standardising the summary document are emerging. The concept and current implementation status of the eNursing Summary was presented at the 10th International HL7 Interoperability Conference 2009 in Kyoto [28] and HL7 is interested in further promoting the topic at international level. IHE (Integrating the Healthcare Enterprise) has taken the position that nursing is central to all patient care activities in terms of consistently providing and coordinating care. The IHE Patient Plan of Care (PPOC) profile is an individualized, framework intended for nurses to provide continuity of care across care settings and time [29]. These different strands which have emerged recently need to be integrated and participation from healthcare providers and industries must to be assured. International harmonization of an eNursingSummary should be addressed in the Joint International Council, where standardisation bodies and organisations like HL7, ISO, CEN, IHTSDO and others work together.

#### Limitations

The eNursing Summary standard we propose was developed using different international sources but has been evaluated so far in Germany only. Further work on mapping the structure and data fields with nursing and discharge letters used in other countries is necessary.

# **Conclusions**

Implementing a standardised electronic nursing discharge and transfer document promises benefits for patients, relatives and healthcare professionals alike. Not only may patients with comorbidities [30], who frequently see different healthcare professionals during an acute episode of their illness, profit but also many other types of patients including elective [31] and emergency patients [32].

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