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[AP3-E2-1-03] A Way of Practical Establishing a Nationwide Shared Dataset for the Continuity of Care, Based on International Standard Dataset

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Keywords: Standardization, Dataset, Patient Summary, Patient Profile

In order to serve the best fitted care to a patient, the health professional has to know full background, which is patient profile, related to this pa-tient's health in addition to the present illness. However, it is very difficult to identify widely acceptable contents of patient profile information (PPI). Here we tried to find a dataset which is very similar to that of PPI and widely accepted. The dataset of the international patient summary was assigned to such a dataset to establish a standard dataset of PPI.

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A Way of Practical Establishing a Nationwide Shared Dataset for the Continuity of Care, Based on International Standard Dataset

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Abstract

In order to serve the best fitted care to a patient, the health professional has to know full background, which is patient profile, related to this patient's health in addition to the present illness. The electronic medical record systems were implemented in many countries for a decade at the beginning of this century and in each country sharing electronic patient summary or electronic health records (EHR) has been tried. Until the present it is not so clear whether those trials are succeeded or not succeeded. It is very difficult to establish widely an acceptable dataset including many items as patient profile information (PPI). On the other hand, international efforts to realize the interoperability of patient summary or EHR data in cross-border have been continued and different types of international standard datasets were developed, e. g. ePS, IPS. Here we compared a dataset of PPI, which we temporally composed, with those international standard datasets. From this study we propose that it is very practical to establish a nationwide shared dataset for the continuity of care, based on a suitable international standard dataset, instead of developing a totally original dataset.

Keywords:

Standardization, Dataset, Patient Summary, Patient Profile

Introduction

In order to serve the best fitted care to a patient, the health professional has to know full background related to this patient's health in addition to the present illness. About fifty years ago, weed called this full background of a patient as patient profile [1]. The importance of patient profile has not been changed, but the contents of patient profile information (PPI), where we add "information" to imagine data elements in patient profile, has not been sufficiently studied. We checked how different the data elements of PPI were among the electronic medical record systems at Japanese sixty hospitals, based on a temporary dataset of PPI [2-3]. That temporary dataset contains 239 items and the number of items implemented in thirty hospitals (a half of hospitals) was only 90 items (38%). Therefore, even if we shared PPI data among hospitals, only rather limited data could be utilized. Any standard dataset is necessary for effectively sharing patient data.

The electronic medical record (EMR) systems were implemented in many countries for a decade at the beginning of this century and in each country sharing electronic patient summary or electronic health records (EHR) has been tried. Until the present it is not so clear whether those trials are succeeded or not succeeded [4-6].

On the other hand, international efforts to realize the interoperability of patient summary or EHR data in cross border have been continued and different types of international standard datasets were developed, e. g. electronic Patient summary (ePS), International Patient Summary (IPS). Here we compared a dataset of PPI, which we temporally composed, with those international standard datasets. We studied whether it was practical or not practical to establish a standard dataset of nationally sharing patient information, based on a suitable international standard dataset.

Materials and Methods

Targets in international standard datasets

PPI is in concept a comprehensive summary for a patient and it is very difficult to completely identify data elements of PPI. Its main purpose is to support healthcare professionals to quickly understand an unscheduled or unanticipated patient. As projects in European Union (EU), international standard of patient summary for cross border patients has been studied since the beginning of this century and several datasets has been developed.

The first dataset was developed in the European Patient Smart Open Services (EpSOS) project from 2008 to 2013 as a use cases of minimum datasets of ePS and e-prescription [7]. Here we refer this ePS dataset as EpSOS-ePS. This dataset categorizes the contents of as basic (minimum) and extended (maximum) PS datasets. Basic dataset of the EpSOS-ePS is defined as the agreed set of essential health information that is required from the clinical point of view to be sent to deliver safe care to the patient focused on unscheduled care. Basic dataset can be either non-mandatory dataset, in which the fields can be filled 'null flavor' if the source system of the country does not track that information, or mandatory basic dataset which all the fields included in it must have a valid value. Extended (maximum) dataset is an agreed extended dataset or desirable health information. This dataset is rather compact dataset and the number of basic data elements are only 33.

The second dataset was developed by European Committee for Standardization-Technical Committee 251 (CEN/TC251), and HL7- International. In April 2017, CEN/TC251 and HL7- International agreed to collaborate on a single common Interna-

tional Patient Summary (IPS) standard that is readily usable by all clinicians for the cross-border unscheduled care of patients. The IPS specification focuses on a minimal and non-exhaustive PS. In 2018, they drafted the first IPS dataset using Advanced Requirement Tooling – Data Elements, Codes, OIDs and Rules (ART-DECOR) and implemented on FHIR-STU3 Version 3.0 [8]. IPS comprises five mandatories and one conditional data blocks [9]. In IPS the necessary levels of data elements are finely assigned as mandatory (M), required (R), required if known (RK), conditional and optional. IPS is more comprehensive than the first dataset and the number of required data elements are more than seventy, including RK elements.

The third dataset was developed by the Joint Initiative Council (JIC) which was a federation of eight global standards development organizations in health informatics in 2015. Eight organizations were CEN/TC251, the International Organization for Standardizations/Technical Committee on Health Informatics (ISO/TC 215), Clinical Data Interchange Standards Consortium (CDISC), GS1 Healthcare, HL7 International, Systematized Nomenclature of Medicine-Clinical Terms (SNOMED-CT) International, Integrating the Healthcare Enterprise (IHE), and Digital Imaging and Communications in Medicine (DICOM). JIC was created to enable common, timely health informatics standards by addressing and resolving issues of gaps, overlaps, and counterproductive standardization efforts. The JIC-Standard Sets Patient Summary (JIC-SS-PS) dataset was designed, based on the definition of Patient Summary as the minimum set of information needed to assure healthcare coordination and the continuity of care [10] and the commonality was stressed for widely use in the world. The volume of this dataset is middle between above two datasets.

Below we focused on these three datasets.

Method to assess comprehensiveness of international standard datasets

In order to understand which international standard datasets are fitted to an establishing dataset, we tried to assess comprehensiveness of each international standard dataset. For this assessment we compared data elements used of our temporary dataset of PPI with those of international datasets.

Results

Comparison between the EpSOS-ePS dataset and a temporary dataset of PPI

The data elements of the EpSOS-ePS dataset are shown in Table 1, compared with a temporary dataset of PPI. The mandatory data elements in the EpSOS-ePS dataset are very few and almost basic data elements are contained in a temporary dataset of PPI. The extended data elements as physical findings and diagnostic tests are not included in PPI.

Table 1- Data elements of the EpSOS-ePS dataset

Data group name	Basic or extended	Mandatory	Data group in PPI
1.1 Patient identification	Basic	Yes	Yes
2.1 Full name	Basic	Yes	Yes
2.2 Date of birth			
2.3 Gender	Basic	No	Yes
3.1 Address, 3.2 Telephone number, 3.3 E-mail, 3.7 Contact person/ legal guardian details	Extended	No	Yes
3.4 Name of preferred healthcare provider (HCP) /legal , organization to contact, 3.5 Telephone no. of the HCP/ legal organization, 3.6 E-mail of the HCP/ legal organization	Basic	No	Yes
4.1 Insurance information	Basic	No	No
5.1 Alerts	Basic 4 Extended 1 items	No	Yes
5.2 History of past illness	Extended 11items	No	Yes
5.3 Medical problems	Basic 9items Extended 4items	No	Yes
5.4Medication summary	Basic7items Extended 1items	No	Yes
5.5 Social History	Extended 2items	No	Yes
5.6.1 Expected date of delivery	Extended	No	No
5.7 Physical findings	Extended 2items	No	No
5.8 Diagnostic tests	Extended 2items	No	No
6.1 Country 6.3 Date of last update	Basic	Yes	No
6.2 Date created 6.4 Author/ nature of the PS 6.5 Responsible of the PS data	Basic	No	No

Comparison between the IPS standard and a temporary dataset of PPI

In Table 2 we show all data items of the IPS standard dataset except conditional and optional items, compared with a temporary dataset of PPI. A large part of the IPS dataset are coincident with a temporary dataset of PPI. However, the data items related to the observation results and the care plan are not included in PPI.

Table 2- Data items of the IPS standard dataset

Data items of IPS standard dataset	**M, R, RK**	**Data items in PPI**
1.1 Patient's name	M	Yes
1.4 Administrative gender	RK	Yes
1.5 Date of birth	R	Yes
1.7 Healthcare related patient identifiers	RK	Yes
1.8 Insurance identifier	RK	Yes
Name of preferred healthcare provider (1.9 person, 1.11 organization)	R	Yes
1Telecoms of preferred healthcare provider (1.10 person, 1.12 organization)	RK	Yes
1.13 Other addressee role	RK	Yes
1.14 Other addressee name	R	Yes
1.16 Other addressee telecoms	RK	Yes
1.17 Name(s) of person(s) authorizing advance directives	RK	No
1.18 Telecoms of person authorizing advance directives	RK	No
2.1Allergy/intolerance description	R	Yes
2.2 Clinical status of the allergy	R	Yes
2.3 Onset date of the allergy	R	Yes
2.9 Manifestation of the reaction	RK	Yes
2.10 Severity of the reaction	RK	Yes
2.11 Allergic agent code	R	Yes
3.1.1 Disability description	R	Yes
3.1.4 Functional assessment description	R	Yes
3.1.5 Date of functional assessment	RK	Yes
3.1.6 Type of functional assessment	RK	No
3.2.1 Types of past health conditions/problems	RK	No
3.2.2 Description of the past illness	R	No
3.2.3 Diagnosis the past illness	R	Yes
3.2.5 Date of onset of the past illness	R	Yes
3.2.7 Date of resolution	R	Yes
3.3.2 Date of observation of the pregnancy	R	No
3.3.3 Pregnancy state	R	Yes
3.3.4 Expected delivery date	RK	No
3.3.8 Date of the previous pregnancy outcome	RK	Yes
3.3.9 Previous pregnancy outcome	R	Yes
3.4.1 Procedure code	R	No
3.4.2 Procedure description	RK	Yes
3.4.4 Procedure date	R	Yes
3.5.1 Vaccine for type of disease	R	Yes
3.5.3 Date of immunization	R	Yes
3.6.1 Devices types	R	No
3.6.2 Devices identifiers	RK	No
3.6.3 Use start date	R	No
3.7.4 Medicinal product's common name (and strength)	RK	Yes
3.7.4 Pharmaceutical dose form	R	Yes
3.7.7 Active ingredient's substance code	R	No
3.7.8 Strength of the active ingredients	R	Yes
3.7.10 Period of medication use	R	No
3.7.12 Number of units of dose per intake	R	Yes
3.7.13 Frequency of intake	R	Yes
3.8.2 Plan date	R	No
3.8.4 Recommendations for treatment	R	No
3.8.5 Given recommendation date	RK	No
3.8.6 Applicable date	RK	No
4.1 Problem type	RK	No
4.2 Problem description	R	Yes
4.3 Diagnosis	R	Yes
4.4 Severity	RK	No
4.5 Onset date	R	Yes
4.7.2 Date of observation	R	No
4.7.3 Observation type	R	No
4.7.4 Result description	R	No
4.7.7 Performer	RK	No
4.7.8 Observer	RK	No
4.8.1 Lifestyle Factors	R	Yes
4.8.2 Lifestyle factor description	R	Yes
4.8.4 Lifestyle factor details	RK	Yes
5.1 Country of affiliation	M	No
5.2 Country specific requirements	RK	No

6.1 Asserter (source information)	RK	No
6.2 Date of IPS	M	No
6.4 Date of last update of IPS content	R	No
6.5 Generation of IPS content: nature of the IPS	R	No
6.6 Authorizing healthcare provider	R	No
6.7 Legal authenticator	RK	No

Comparison between the JIC-SS-PS dataset and a temporary dataset of PPI

In Table 3 we show required data items of the JIC-SS-PS dataset, compared with a temporary dataset of PPI. Although "Patient Name" consists of "Family name/surname" and "Given or first name" as the core data element in the JIC-SS-PS dataset, we denote just "Patient Name" as the data item in Table 3. The medical terms in the JIC-SS-PS dataset are preferable to be used the SONOMED-CT terms. Since the medical terms in PPI are not referred to the SONOMED-CT terms, those data items are denoted as “No” in PPI.

Table 3- Required data items of the JIC-SS-PS dataset

Data items of the JIC-SS-PS dataset	**Data items in PPI**
1. Demographic/non-clinical data items	
(Patient)	
Patient name	Yes
Primary: regional/ national health id	Yes
Address	Yes
Telephone	Yes
E-mail	Yes
Preferred language of the patient	Yes
(Responsible healthcare professional/document author section)	
Preferred healthcare provider name	Yes
ID number of preferred healthcare provider	Yes
Telephone of preferred healthcare provider	Yes
E-mail of preferred healthcare provider	No
(Document identification section)	
Date of creation and last update	No
Author Organization	No
2. Clinical Data items	
(Allergies section)	
Allergy type	Yes
Allergy substance category	Yes
Allergy onset date	Yes
Reaction	Yes
Severity of reaction	Yes
Agent description (allergen description or name)	Yes
Agent code (Allergen code)	Yes
(Vaccinations)	
Vaccination name	Yes
(Problems (Illnesses, Diseases, Diagnoses) – Current)	
Current Health Condition Description (health issue)	Yes
Problem code (SNOMED preferable)	No
Problem onset date	Yes
(Problems Resolved, closed or inactive)	
Problem Description	Yes
Problem ID code (SNOMED preferable)	No
Onset date	Yes
End date	No
(Procedures (investigative, diagnostic or treatment))	
Surgical procedure, non-invasive procedure or intervention and other procedure description	Partially Yes
Procedure code	No
Procedure date	Yes
(Competency/capacity/ invalidity)	
Decision making Competency or invalidity description	Partially Yes
Invalidity ID code	No
(Medications)	
(Name brand or generic) or active ingredient description (active ingredient name)	Yes
Medication brand code or active ingredient code	Yes
Detail prescription (Strength, Pharmaceutical dose form, Number of units per intake, Frequency of intake, Duration of treatment)	Partially Yes
Date of start of treatment	Yes
(Diagnostic test results - blood group)	
Blood group observation description (name) (blood group only)	No

Discussions

The projects of the ePS standardization in EU are very suggestive for establishing a nationwide shared dataset in each country. The standard dataset of the ePS developed by EpSOS had a simple structure; a little mandatory and basic and extended elements. Since the mandatory contents was rather limited, many countries could accept this standard dataset. At Estonia

the epSOS project's definition of a patient summary was used as a general guideline to build the electronic patient summary and the electronic prescription dataset in 2010 [11].

At the next step to the IPS, the structure of the standard dataset became a little complex and required contents were largely increased, equal or more than the contents of a temporary dataset of PPI. The IPS dataset seems to be helpful for establishing more comprehensive patient summary like a PPI dataset.

In the JIC-SS-PS dataset use of the SNOMED-CT terms is preferable and the size of the dataset is not so small and not so large. If the SNOMED-CT terms are acceptable, this dataset is suitable to establish a middle sized dataset like a discharge summary dataset.

The international efforts until the present shows us the direction to establishing an international standard dataset: Start with the low required level and next the required level was lifted up step by step. When we develop a nationwide shared dataset, at beginning we have to reduce the required contents in the standard dataset, choose a suitable international standard dataset fitted to our purposes and adjust it, considering own country's health system, culture and so on. We propose that this approach is very practical for establishing a nationwide shared dataset for the continuity of care at each country.

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