Converging Patient Summaries: Finding the Common Denominator between the European Patient Summary and the US-Based Continuity of Care Document

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Abstract

Having the administrative and clinical information concerning the patient presented in a comprehensible format, language, and terminology is valuable for any healthcare provider. In Europe, this type of information is represented by the Patient Summary Guideline and on the other side of the Atlantic by the Continuity of Care Document (CCD). Trillium Bridge is a project co-funded by the European Commission that "compares specifications of EU and US patient summaries with the aim of developing and testing common and consistent specifications and systems enabling interoperability of electronic health records across the Atlantic." The objective of this article is to summarize the findings of the comparison between these two Patient Summaries. Both documents are using the same syntax, namely Clinical Document Architecture (CDA), making the comparison easier.

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Ana Estelrich Phast Address: 17 Rue de Louvre, 75001 Paris France E–mail: ana.estelrich@phast.fr The documents were compared from a clinical, syntactic, and terminological point of view focusing on semantic interoperability. A common denominator was found in terms of sections, data elements, and value sets. Comparing the value sets led the project team to assess available official maps such as the SNOMED CT and ICD-10 and determine their applicability. In some cases, such as the National Cancer Institute Thesaurus and the EDQM standard terms, no maps were found and the team proposed associations. The common denominator thus identified allows for significant parts of the data to be exchanged, setting the baseline for the transatlantic exchange of a meaningful set of patient summary data and establishing a springboard for an international patient summary standard.

Keywords

Semantic interoperability, code system maps, EU-US MoU, Patient Summary guideline

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1 Introduction

1.1 Patient Summaries Initiatives in Europe and the United States

Concise, unambiguous health information is of paramount importance for the healthcare provider administering care to his or her patient. This becomes even more important in cases of cross-border care, where the patient might not speak the language or understand the subtleties of the local culture. The information that is most useful to a healthcare provider is of administrative, demographic, and clinical nature.

Most often this information is present in what is known as a Patient Summary and is available in various formats in the Member States (MS) of the European Union, leading to a variety of regional and national Patient Summaries. The information is represented by discrete data elements, which were harmonized by the European Patient Smart Open Services (epSOS) [1], a large scale eHealth pilot project co-funded by the European commission (EC) focusing on issues related to the communication of patient summary data in situations of emergency or unplanned care, in a cross-border context. The epSOS Patient Sum-

epSOS/EU Directive	EU PS [2]	epSOS PS [7]	CCD [8]	CCD
Section	$\begin{array}{c} \mathbf{Guidelines}\\ Optionality \end{array}$	Optionality	Section	Optionality
Allergy	R	R	Allergies	R
List of current medicines	R	R	Medications	R
List of current	R	R	Problem	R
problems/diagnoses				
Surgical Procedures prior	R	Ο	Procedures	O (R only
to the past six months				for inpatients)
Major Surgical Procedures	R	R	Procedures	O (R only
in the past six months				for inpatients)
Medical Devices and implants	R	R	Medical Equipment	0
Vaccinations	0	0	Immunizations	0
Social History Observations	0	0	Social History	0
Pregnancy history	0	0	Social History	0
(Expected date of delivery)			(Pregnancy Observation)	
Physical findings	0	0	Vital Signs	0
(Vital Signs Observations)			-	
Diagnostic tests (Blood group)	0	0	Results Section	R
Treatment Recommendations	R	0	Plan of Care	0
Autonomy/Invalidity	R	0	Functional Status	0
Not matched			Advance Directives	0
Not matched			Family History	0
Not matched			Payer	0
Not matched			Encounters	0
List of resolved,	0	0	Not matched	
closed or inactive problems				
(History of Past Illness)				

Table 1: Section Comparis	on between the epSOS PS,	EU PS Guideline, and CCD.
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mary services were further incorporated in the European Guideline on Patient Summary minimum/non exhaustive data set for electronic exchange under the cross-border directive 2011/24/EU [2, 3] in May 2013 during the 3rd meeting of the of the eHealth Network [4]. These guidelines support the objective of continuity of care and patient safety across borders, focusing on emergency or unplanned care in a cross-border context and indicate the minimum data set to be used in the cross-border exchange of patient summaries in the pan-European space. The guidelines also make non-binding recommendations on the syntax (CDA) and the various terminologies and value sets to be used in the electronic documents to be exchanged.

On the other side of the Atlantic, the US Department of Health & Human Services (HHS) Office of the National Coordinator for Health Information Technology (ONC) defines certified Electronic Health Records technology through a series of "Meaningful Use" regulations, the current one being the Meaningful Use 2 (MU-2) that are next linked to provider incentives [5]. Part of these regulations applies to electronically-produced medical documents also based on a CDA compliant syntax. For example, MU-2 refers to C-CDA specifies the data elements, syntax and terminologies for several document types, i.e. Consult Note, Diagnostic Imaging Report, Discharge Summary, History and Physical, Operative Note, Procedure Note, Progress Note, and Continuity of Care Document (CCD). Among these, the Continuity of Care Document (CCD) is defined as a "core data set of the most relevant administrative, demographic, and clinical information facts about a patient's healthcare" allowing the aggregation of all of the pertinent patient data to be forwarded to another practitioner, system, or setting so as to support the continuity of care.

1.2 EU/US Cooperation and the Trillium Bridge Project

A Memorandum of Understanding [6] between the United States Department of Health and Human Services and the European Commission on cooperation surrounding health related information and communication technologies (ICT) was signed in 2010. The main objectives of this MoU, namely the "... cooperation on topics directly pertaining to the use and advancement of eHealth/health IT, in pursuit of improved health and health care delivery as well as economic growth and innovation..." and "... the development of internationally recognized and utilized interoperability standards and interoperability specifications for electronic health record systems that meet high standards for security and privacy protection..." are reflected in the aims of the Trillium Bridge Project.

The Trillium Bridge Project co-funded by the European Commission, compares from a semantic point of view the epSOS Patient Summary and the CCD documents investigating if a common area of exchange is possible and what is necessary to accomplish the baseline exchange and shared understanding of the relevant patient summary data.

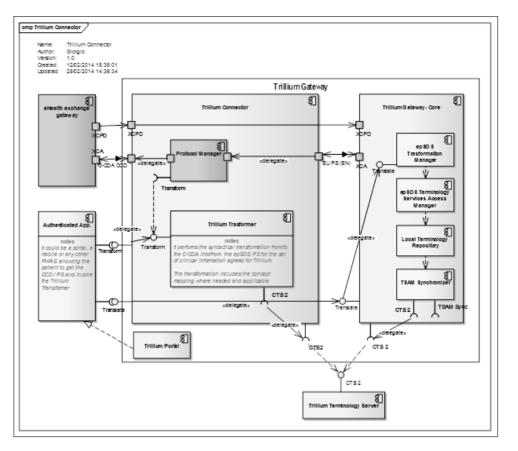


Figure 1: Trillium Gateway: transformation, terminology, and translation componentss.

2 Methods

The two patient summary specifications from each side of the Atlantic were compared with several lenses: their intended used, consisting sections, data elements, syntax and value sets. A common intersection area was identified.

The intended use of the two documents, the epSOS Patient Summary (epSOS PS) [7] and the Consolidated CDA Continuity of Care Document (CCD Release 1.1, hereafter simply indicated as CCD) [8] and the detailed composition of their respective sections were studied. Corresponding sections were investigated from a functional definition perspective. Within each section there are several data elements. Particular attention was paid to the data elements that contained value sets and to the functional rules concerning the syntactic transformation that had to be applied. In case of different value sets, the code systems were identified and official mappings were sought. The official mapping were further investigated in terms of their applicability to the content of the value sets. Where no official maps were found, mapping was done by the Trillium Bridge Project team. The code systems, value sets and the mappings were uploaded in a Common Terminology Services Release 2 (CTS2) terminology server and its contents are available online. A transformer currently under development, uses the CTS2 web service (http://extension.phast.fr/STS UI) in mapping structure and semantics in actual patient summaries.

3 Results

3.1 Comparison at the Document Level

The intended clinical meaning of the epSOS PS and CCD were listed in the introduction. Although CCD has a much wider scope and is intended to facilitate the patient transfer from one healthcare provider to another, it can be safely concluded that in principle, both documents contain the same type of information: clinical, demographic and administrative data at one particular point in time.

3.2 Comparison at the Section Level

The content of the documents is compared in Table 1. Although, to our knowledge, there are no implementations of the European Patient Summary (EU-PS) Summary guideline, it has been included as it is the future direction of implementation in Europe under the Connecting Europe Facility (CEF), which aims to support large scale eHealth deployment. However, it must be noted that since there are no implementations of the EU Patient Summary, the epSOS PS implementation guide has been used throughout the rest of the project and is referenced in all the results and discussions.

There are three common sections which are required in both documents – they are deemed as the common intersection between the two documents which will always

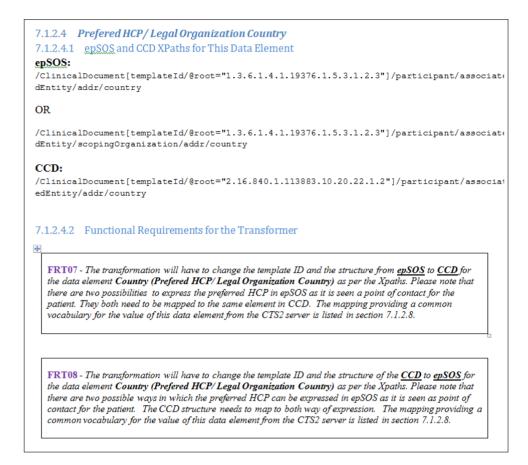


Figure 2: Example of transformation rules concerning the healthcare professional role [10].

be present as they are mandatory on both sides of the Atlantic (first three lines in Table 1). There are nine sections that are required in one document but are optional in the other, as well as sections that are optional in both documents – there are considered as the possible common intersection between the two documents (next nine lines in Table 1). There are two sections that are present as text only (next two lines in Table 1) such as the Treatment Recommendations and the Autonomy/Invalidity. These are mentioned for completeness, but are not included in the analysis. Lastly, there are four sections that are present in one document, but not present in the other document – these sections are not considered to be part of the common ground between the two documents (last four lines in Table 1).

Some additional information concerning several sections is necessary. Both the Surgical Procedures prior to the past six months and the Major Surgical Procedures in the past six months, use the Coded List of Surgeries section. The only indication differentiating them is the Date. The History of Past Illness section in the epSOS PS it is rarely used and only by a few MS. Furthermore, it does not have a direct correspondence in the CCD. Although CCD is an open document template and any of the section templates can theoretically be added to it, the chances of this section being present in a routine clinical document originating from the US side are very slim, hence it is not considered as having an equivalent. With these consideration in mind, there are 11 sections out of the 15 present in the epSOS PS have correspondence in the US CCD, and 11 sections out of the 15 present in the CCD have correspondence in epSOS. A detailed analysis of the comparison is available in [9].

3.3 Transformable Coded Data Elements

Within the common sections, there are common data elements conveying the same semantic meaning using two types of content: structural elements and terms bound Trillium Bridge uses a set of to specific value sets. XSLT transformations to ensure their correct interpretation. The structural elements will be transferred as they are between the two sides of the Atlantic with the understanding that the template identifiers will be changed. In case that a structural element is not present, the default value from the recepient specification will be used. The value elements will be transformed according to wellspecified functional rules and contextual mappings of their value sets. Figure 1 shows the information flow, the transformation process, and the integration with the CTS2 server, while Figure 2 shows an example of the transformation rules used [10, 11].

epSOS Code	epSOS Display Name	CCD Code	CCD Display Name
419199007	Allergy to substance	419199007	Allergy to substance (disorder)
416098002	Drug allergy	416098002	Drug allergy (disorder)
59037007	Drug intolerance	59037007	Drug intolerance (disorder)
414285001	Food allergy	414285001	Food allergy (disorder)
235719002	Food intolerance	235719002	Food intolerance (disorder)
420134006	Propensity to adverse	420134006	Propensity to adverse
	reactions		reactions (disorder)
419511003	Propensity to adverse	419511003	Propensity to adverse
	reactions to drug		reactions to drug (disorder)
418471000	Propensity to adverse	418471000	Propensity to adverse
	reactions to food		reactions to food (disorder)
418038007	Propensity to adverse	418038007	Propensity to adverse
	reactions to substance		reactions to substance (disor-
			der)

Table 2: Mapping between the value sets epSOSAdverseEventType and CCD Allergy/Adverse Event Type.

Table 3: Mapping between the value sets epSOSRoleClass and CCD INDRoleclassCodes.

epSOS Code	epSOS Display Name	CCD Code	CCD Display Name
ECON	emergency contact	ECON	RoleClass
NOK	next of kin	NOK	RoleClass
	no match	PRS	RoleClass
	no match	CAREGIVER	RoleClass
	no match	AGNT	RoleClass
	no match	GUAR	RoleClass
	no match	ECON	RoleClass

3.4 Comparison of the Value Sets

The value sets used in the coded data elements present in the two documents are referenced in the same usage context. Thus, when comparing value sets two cases can be distinguished: value sets whose concepts are based on the same code system and value sets that are based on different code systems. Below each case is explained in turn.

Value sets that are based on the same code system

Within the value sets that are based on the same code system there are cases where there is a perfect match between the concepts of the value sets. Table 2 presents such a case for the value sets of Adverse Event Types related to Allergies in epSOS and CCD.

These cases are unfortunately rare since requirements are typically formulated differently by the healthcare professionals on the two sides of the Atlantic. In most cases, where the code system is the same, there is usually a partial overlap between the two value sets. Table 3 and 4 present such examples.

Value sets that are based on different code systems

Alternatively the value sets bound to corresponding can be based on different code systems. In some cases there are official maps that are available for use, such as the maps provided by IHTSDO between SNOMED CT and ICD-10 and by the National Library of Medicine (NLM) between SNOMED CT and ICD-10-CM [12] as well as RxNorm, NDF-RT and ATC. The official maps had to be studied in order to determine their applicability to the contents of the value sets. Within the maps supplied by IHTSDO and NLM between SNOMED CT and ICD-10, not all the terms have an unambiguous mapping – some are context-dependent or rule-based. For example, the target term may depend on gender and age of onset. Trillium Bridge selected from the official mappings only the ones where:

- mapRule is equal "TRUE" and "OTHERWISE TRUE", independent of context¹,
- mapAdvice indicates ALWAYS a code
- mapCategoryValue indicates that Map source concept is properly classified
- mapTarget contains always an ICD-10 code.

 $^{^1}$ For more information please see the document Mapping SNOMED CT to ICD-10 Technical Specifications that comes with the SNOMED CT distribution [12].

epSOS Code	epSOS Display Name	CCD Code	CCD Display Name
WP	work place	WP	work place
MC	mobile contact	MC	mobile contact
HV	vacation home	HV	vacation home
HP	primary home	HP	primary home
\mathbf{PG}	Pager	Not matched	
Н	Home	Not matched	
\mathbf{EC}	emergency contact	Not matched	
AS	answering service	Not matched	

Table 4: Mapping between the value sets epSOSTelecomAddress and CCD Telecom Use (US Realm Header).

- The ICD-10 codes are included in cases that a code was ALWAYS listed with the additional recommendations:
 - possible requirement for an external cause code
 - consider additional code to identify specific condition or disease
 - descendants not exhaustively mapped
 - consider raterality specification
 - additional codes may be required to identify place of occurrence
 - possible requirement for causative disease code
 - consider trimester specification.
- The ICD-10 codes were excluded when:
 - Use as primary code only if site of corrosion unspecified, otherise use as supplementary code with categories T20-T25 (Burns)
 - This is an external cause code for use in a secondary position
 - This is a manifestation for use in a secondary position
 - This is an infectious agent code for use in a secondary position

Although this is an oversimplyfication, it is necessary as there are no means to select the appropriate term based on contextual rules in Trillium Bridge. Moreover, after eliminating rule-based associations according to the guidance provided above, there are still one-to-many mappings as shown in the example of Table 5. Such one-to-many mappings had to be excluded from the Trillium Bridge association maps as they would have put the healthcare provider at the receiving end into a dilemma as to which one to chose without any background information. This decision to exclude one-to-many mappings reduced dramatically the size of the maps.

The last consideration regarding the official mappings is their applicability to the concepts present in the value sets. Not all the concepts present in the value sets are included in the official maps. In the case of the other set of official maps supplied by NLM between RxNorm (describing the clinical drug name and the brand name)

and the NDF-RT (drug class) and ATC the synonyms in the mappings were excluded – a code was used only once. The statistics on the official maps and the percentage of coverage they provide to the Trillium Bridge Project are presented in table in Appendix 1.

In some cases, where the value sets are based on different code systems no official mapping was found. In these cases the mapping between the various concepts belonging to the value sets were done by the project team and need a rigurous quality assurance by subject matter experts. The mappings cover concepts in the following code systems:

- ISCO-08 NUCC (International Standard Classification of Occupations 2008 and The National Uniform Claim Committee)
- EDQM Standard terms NCI thesaurus (National Cancer Institute Thesaurus)
- SNOMED CT CVX (Vaccine Administered)
- UNII SNOMED CT (Unique Ingredient Identifier from FDA)

The results of all the value set mappings are summarized in table in Appendix 1.

4 Discussion

A considerable amount of work went into the analysis of the semantic components of the epSOS Patient Summary and the Continuity of Care (CCD) document specifications. Sections were compared based on data elements contained by the sections, followed by the value sets. Although the documents are different and were originally intended for slightly different purposes (CCD for is intented for planned and unplanned care and epSOS PS for unplanned care), there is a considerable amount of overlap in the clinical information present. However, the way the structure is expressed brings forth the need for syntactic transformation. The epSOS Patient Summary and likewise the EU PS guidelines are based on IHE content profiles. CCD is a document type in Consolidated CDA (CCDA), which is the result of harmonization of CDA implementation guides developed independently by IHE, HealthStory and HL7. This can explain the differences in

SNOMED CT code	SNOMED CT designation	ICD-10-CM code	ICD-10 designation
193003	Benign hypertensive renal disease	I12.9	Hypertensive renal disease
			without renal failure
193003	Benign hypertensive renal disease	N18.9	Chronic kidney disease,
			unspecified
2355008	Rud Syndrome	Q80.3	Congenital bullous
			ichthyosiform erythroderma
2355008	Rud Syndrome	F79	Unspecified intellectual
			disabilities
2355008	Rud Syndrome	Q87.1	Congenital malform
			syndromes predom assoc
			w short stature

Table 5: Example of one-to-many mappings in the official files from IHTSDO and NLM that were excluded.

the way the clinical information is syntactically expressed. A transformer can help with this syntactic conversion in the short term, but in the long term, a formal consolidation process would be necessary.

However, syntax represents only half of the semantic components. The value sets that are used in the data elements of the CD data type also need to be mapped. In some cases, only some of the value sets have equivalence on both sides. The difference between the uses of the value sets can be attributed to the different clinical needs identified by the healthcare professionals who contributed to the development of the specifications in Europe and the US.

Trillium Bridge performed a feasibility study consisting of comparing the two document specifications and their associated vocabularies and value sets. It is important to acknowledge that this exercise does not claim to solve all interoperability and terminology issues, nor is a finite, one-time endeavor. A first attempt to mapping is put forth to establish the baseline for testing and implementation and provide evidence for policy decisions. However, it is expected that quality assurance will continue throughout the reminder of the project and well afterwards, once the proper processes and infrastructure are in place. Our study laid the basis for a feasibility study answering the question: Can an exchange of documents take place between the Europe and USA, and can there be any meaningful information transferred between the two sides?

Mapping between terminologies is a complex activity, which needs to be continued with the proper subject matter experts on board. It is important that the subject matter experts include not only medical personnel, but also academic and research representatives as well as experts from governments and the industry. Most importantly, the presence and participation of Standards Development Organizations such as IHTSDO and WHO, is necessary.

The results of the feasibility study so far indicate that there are value sets that are much richer in content and granularity on either side of the Atlantic and that a common denominator must be found to establish the basis for the exchange patient information. However, this common denominator results in loss of clinical information as it is neither specific nor granular enough. The original code and original document must be always sent as to preserve the original intended meaning. The transformed/transcoded information should be used for information purposes only by the patient and the receiving clinicians.

In retrospect, there is clear value in the efforts undertaken by the Trillium Bridge project because working to establish a baseline for interoperability has advanced cooperation and mutual understanding among experts in the two sides of the Atlantic. Moreover, the information and knowledge gained can initiate harmonization in the syntax and the terminologies used in the patient summary specifications and hopefully lead to the development of an international patient summary standard.

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epSOS Value Set	epSOS Code System	epSOS %covered	CCD Value Set	CCD Code System	CCD % covered
epSOSAdministrativeGe nder	HL7 AdministrativeGender	3/3 (100%)	Administrative Gender (HL7)	HL7 AdministrativeGender	3/3 (100%)
epSOSCountry	ISO 3166-1 Country Codes	43/43 (100%)	CountryValueSet	ISO 3166-1 Country Codes	43/244 (18%)
epSOSEntityNamePartQ ualifier	HL7 EntityNamePartQualifi er	10/11 (91%)	EntityNamePartQualifier	HL7 EntityNamePartQualifier	10/10 (100%)
epSOSHealthcareProfess ionalRoles	ISCO-08	30/39 (77%)	Provider Type	NUCC	104/232 (45%)
epSOSConfidentiality	HL7 Confidentiality	3/7 (43%)	HL7 BasicConfidentialityKind	HL7 Confidentiality	3/3 (100%)
epSOSLanguage	ISO 639-1	35/35 (100%)	Language	ISO 639-1	35/184 (19%)
epSOSPersonalRelations hip	HL7 RoleCode	39/39 (100%)	Personal Relationship Role Type	HL7 RoleCode	39/104 (38%)
epSOSTelecomAddress	HL7 AddressUse	4/8 (100%)	Telecom Use (US Realm Header)	HL7 AddressUse	4/4 (100%)
epSOSRoleClass	HL7 RoleClass	2/2 (100%)	INDRoleclassCodes	HL7 RoleClass	2/6 (33%)
epSOSReactionAllergy	SNOMED CT	6/9 (67%)	Problem	SNOMED CT	6/16,443 (0.04%)
epSOSAdverseEventTyp	SNOMED CT	9/9 (100%)	Allergy/Adverse Event Type	SNOMED CT	9/9 (100%)
epSOSActiveIngredient	ATC	606/5592 (6%)	Medication Drug Class	NDF-RT	1365/10699 (13%)
epSOSActiveIngredient	ATC	2836/5592 (51%)	Medication Brand Name	RxNorm	3329/13885 (24%)
epSOSActiveIngredient	ATC	2836/5592 (51%)	Medication Clinical Drug	RxNorm	9642/31214 (31%)
epSOSAllergenNoDrugs	SNOMED CT	79/112 (71%)	Ingredient Name	UNII	5315/63996 (8%)*
epSOSRoutesofAdminist ration	EDQM Standard Terms	55/73 (75%)	Medication Route FDA	NCI Thesaurus	57/118 (48%)
epSOSDoseForm	EDQM Standard Terms	28/457 (6%)	Medication Product Form	NCI Thesaurus	99/153 (65%)
epSOSUnits	UCUM	77/77 (100%)	UCUM Units of Measure	UCUM	77/557 (14%)
epSOSUnits	UCUM	6/77 (8%)	AgePQ_UCUM	UCUM	6/6 (100%)
epSOSIIInessesandDisor ders	ICD-10	1775/9525 (19%) IHTSDO maps	Problem	SNOMED CT	7204/16443 (44%) IHTSDO maps
epSOSIIInessesandDisor ders	ICD-10	1147/9525 (12%) NLM maps	Problem	SNOMED CT	6914/16443 (42%) NLM maps
epSOSCodeProb	SNOMED CT	7/7 (100%)	Problem Type	SNOMED CT	7/8 (88%)
epSOSStatusCode	SNOMED CT	3/8 (38%)	HITSPProblemStatus	SNOMED CT	3/3 (100%)
epSOSResolutionOutco me	SNOMED CT	7/8 (88%)	HealthStatus	SNOMED CT	7/7 (100%)
epSOSProcedures	SNOMED CT	102/102 (100%)	no specific value set, whole code system	SNOMED CT	N/A
epSOSMedicalDevices	SNOMED CT	70/70 (100%)	no specific value set, whole code system	SNOMED CT	N/A
epSOSVaccine	SNOMED CT	27/31 (87%)	Vaccine Administered	SNOMED CT	87/163 (53%)
epSOSSocialHistory	SNOMED CT	8/8 (100%)	Social History Type Set Definition	SNOMED CT	8/9 (100%)
epSOSPregnancyInform ation	LOINC	3/3 (100%)	no specific value set, whole code system	LOINC	N/A
epSOSBloodGroup	SNOMED CT	12/12 (100%)	no specific value set, whole code system	SNOMED CT	N/A
epSOSBloodPressure	LOINC	2/2 (100%)	HITSP Vital Sign Result Type	LOINC	2/12 (1.7%)

Appendix 1: The Trillium value set mappings with % covered (concents with correspondence/concepts present)