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

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WWW.TRILLIUMBRIDGE.EU
Outline of the talk

What is a patient summary?

The Trillium Bridge project

Our findings on leveraging standards, implementation guides and mapping

Stepping back

What do we learn from this exercise?

How can we use it towards larger global impact?

Large scale eHealth deployment in Europe

Supporting actions coming up in 2014 and later
What is a patient summary?

- **Discharge summary (EU and US)**
  - Summary of a hospital admission

- **Encounter Report (EU) or Clinical Summary (US)**
  - Subjective, objective, assessment, plan

- **Continuity of Care Record / Blue Button (US)**
  - Moving to one physician to another; referral

- **Travelers Record (IMIA/AMIA/EFMI)**
  - Safe while traveling, e.g. a letter from your doctor

- **Patient Summary (EU)**
  - Essential health data that should be communicated in the context of emergency or unplanned care (i.e. allergies, medication, problems, etc)

How is it created?

- By the physician or automatically?

What standards/terminologies does it use?

- Is it trusted? Up-to-date? Understood?

How is it used?
EU patient summary guideline defines patient summary as the “minimum set of information needed to assure healthcare coordination and continuity of care”

Emergency or unplanned care refers to “the range of healthcare services available to people who need medical advice, diagnosis and/or treatment quickly and unexpectedly”

Other EHR summaries
- Emergency data set
- Continuity of care record
- Encounter report
- Discharge summary
- 2\textsuperscript{nd} opinion
- Clinical patient summary
- Disease specific summaries

Around the world many variants of the same basic types of patient summaries

HL7 Consolidated CDA
- seven document types, seven of which were consolidated in CCDA
Patient summaries in the USA
Clinical patient summary, US Meaningful Use

§ 170.314(b) Care Coordination

1. Transitions of care - receive, display, and incorporate transition of care/referral summaries.
   - Incorporate medications, problems, allergies
   - Create C-CDA
   - Medications, problems, allergies
7. Data portability.

§ 170.314(e) Patient Engagement

1. View, download, and transmit to 3rd party clinical summary
   - Patient’s ability to download clinical summary in HL7 C-CDA CCD
2. Ambulatory setting only - clinical summary.
   - Patient receives patient summary after encounter
## Blue Button+

<table>
<thead>
<tr>
<th>HL7 C-CDA Sections</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Header</td>
<td>Patient information demographics</td>
</tr>
<tr>
<td>Allergies, Adverse Reactions, Alerts</td>
<td>Includes status and severity of each.</td>
</tr>
<tr>
<td>Encounters</td>
<td>Surgeries, ED visits, etc.</td>
</tr>
<tr>
<td>Immunizations</td>
<td>Immunizations and vaccines</td>
</tr>
<tr>
<td>Medications</td>
<td>As prescribed by the provider</td>
</tr>
<tr>
<td>Care Plan</td>
<td>Planned activities and encounters</td>
</tr>
<tr>
<td>Discharge Medications</td>
<td>Part of hospital discharge summary</td>
</tr>
<tr>
<td>Reason for Referral</td>
<td>Written reason for referral</td>
</tr>
<tr>
<td>Problem List</td>
<td>Concerns, complaints, and observations</td>
</tr>
<tr>
<td>Procedures</td>
<td>History of procedures</td>
</tr>
<tr>
<td>Functional &amp; Cognitive Status</td>
<td>List of impairments</td>
</tr>
<tr>
<td>Results</td>
<td>Includes laboratory tests</td>
</tr>
<tr>
<td>Social History</td>
<td>Observations like smoking, drinking, etc.</td>
</tr>
<tr>
<td>Vital Signs</td>
<td>Includes height, weight, blood pressure, etc</td>
</tr>
<tr>
<td>Discharge Instructions</td>
<td>Written discharge instructions</td>
</tr>
</tbody>
</table>

http://bluebuttontoolkit.healthit.gov/
eHealth market is demanding!

HL7 CDA is a powerful tool for incremental interoperability

- Endorsed and adopted by several governments
- Constrained with Templates and Implementation Guides
  - Developed independently... a cost to interoperability

eHealth market calls for agile processes

- Interoperability to lower costs
- plug-n-play interoperability assets

Can HIT Standards do better?

- Be the safety net that strengthens the fabric of the global ehealth ecosystem
- Enable Culture of collaboration for creativity, and understanding
- Make interoperability Affordable, built once, use anywhere, across borders
The main question for Trillium Bridge..

Is it feasible to convert a patient summary generated in the European Union according to epSOS specifications to one that is fit for use in the United States?

Our Action: Compared clinically, syntactically and semantically the European PS (epSOS) and MU clinical summary (HL7 CCDA/CCD)

- Evidence
  - use specs & examples, carry out tests
- Feasibility study
  - what have we learned and what are the implications?
Trillium Bridge Project: a feasibility study and builder perspective...

The problem

- What can we do to lower the cost of transatlantic business engagement in eHealth?
  - Reduce barriers for transatlantic coordination, health care, trade
  - Decrease standards development and implementation costs
  - Accelerate convergence towards global standards
  - Support right of citizens to their health data and safety

- Well, perhaps we could try building...
  - ...a Transatlantic Bridge for EHR summaries!

The Solution

- Pragmatic Feasibility study on the exchange of Patient Summaries across the Atlantic
  - Compare, analyze, and map EU/US patient summaries starting with Meaningful Use 2 C-CDA/CCD and EU patient summaries (epSOS)
  - July 2013 to June 2015

- Stellar consortium of EU member state provider networks, associations, SDOs
Trillium Bridge: methodology

Building the Transatlantic bridge for EHR patient summaries

- Complete Gap analysis
  - User stories, use cases, business architecture, D2.2
- Identify interoperability Assets
  - Established STS terminology service associating EU/US terms, D3.1
  - Proof of concept transformer of EHR structures and semantics, D3.2
- Inform and support standardization efforts
  - Ground work of an Intl EHR patient summary
  - Aligning infrastructure, D4.1
- Refine assets, work on the puzzle through validation
  - Test with EU countries and US providers, D4.2
  - Set the tone and pace for interoperability in the global eHealth ecosystem, D5.1, 5.2

Attain the vision and aims of EU-US of the eHealth MoU and roadmap!
Trillium Bridge Use Cases

**One Value proposition:**
- When patient needs unplanned care overseas, a EHR summary fit for the purpose of safe and efficient health care is available.
- After the health care encounter, patient receives encounter report in a format and language that can be understood back home.

**Two use cases:**
- Provider mediated (citizen controlled, provider initiated)
- Patient mediated (citizen initiated, citizen controlled)

**Blazing the transatlantic path – constraints and assumptions**
- Translation of narrative unstructured content (not in scope)
- Incorporate patient summary elements in EHR or PHR (not in scope)
- Preconditions: citizen empowerment
  - EU Citizens have access to their EU Patient Summary (e.g. epSOS PAC)
  - US Citizens have access to their Clinical Summary in C-CDA/ CCD
Comparison of EHR summaries and the International Patient Summary bottom line

- Same base Standard (HL7 CDA)
- Different philosophy: capture vs continuity of care
- Different IGs: C-CDA/CCD (US realm) vs epSOS IG
- Different technical approach: Open vs Closed Template
### Section Comparison

**epSOS: 15 sections, 1 not mapped, 2 grouped = 12 sections**  
**CCD: 15 sections, 4 not mapped = 11 sections**

<table>
<thead>
<tr>
<th>epSOS/EU Directive</th>
<th>EU Patient Guidelines</th>
<th>epSOS PS</th>
<th>CCD</th>
<th>Optionality</th>
</tr>
</thead>
<tbody>
<tr>
<td>Section</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Allergy</td>
<td>R</td>
<td>R</td>
<td>Allergies</td>
<td>R</td>
</tr>
<tr>
<td>List of current medicines</td>
<td>R</td>
<td>R</td>
<td>Medications</td>
<td>R</td>
</tr>
<tr>
<td>List of current problems / diagnoses</td>
<td>R</td>
<td>R</td>
<td>Problem</td>
<td>R</td>
</tr>
<tr>
<td>Surgical Procedures prior to the past six months</td>
<td>R</td>
<td>O</td>
<td>Procedures</td>
<td>O(R only for inpatients)</td>
</tr>
<tr>
<td>Major Surgical Procedures in the past six months</td>
<td>R</td>
<td>R</td>
<td>Procedures</td>
<td>O(R only for inpatients)</td>
</tr>
<tr>
<td>Medical Devices and implants</td>
<td>R</td>
<td>R</td>
<td>Medical Equipment</td>
<td>O</td>
</tr>
<tr>
<td>Vaccinations</td>
<td>O</td>
<td>O</td>
<td>Immunizations</td>
<td>O</td>
</tr>
<tr>
<td>List of resolved, closed or inactive problems</td>
<td>O</td>
<td>O</td>
<td>Problem</td>
<td>R</td>
</tr>
<tr>
<td>Social History Observations</td>
<td>O</td>
<td>O</td>
<td>Social History</td>
<td>O</td>
</tr>
<tr>
<td>Pregnancy history (Expected date of delivery)</td>
<td>O</td>
<td>O</td>
<td>Social History (Pregnancy Observation)</td>
<td>O</td>
</tr>
<tr>
<td>Physical findings (Vital Signs Observations)</td>
<td>O</td>
<td>O</td>
<td>Vital Signs</td>
<td>O</td>
</tr>
<tr>
<td>Diagnostic tests (Blood group)</td>
<td>O</td>
<td>O</td>
<td>Results Section</td>
<td>R</td>
</tr>
<tr>
<td>Treatment Recommendations</td>
<td>R</td>
<td>O</td>
<td>Plan of Care</td>
<td>O</td>
</tr>
<tr>
<td>Autonomy / Invalidity</td>
<td>R</td>
<td>O</td>
<td>Functional Status</td>
<td>O</td>
</tr>
<tr>
<td>History of Past Illness</td>
<td>O</td>
<td></td>
<td>Advance Directives</td>
<td>O</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Family History</td>
<td>O</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Payer</td>
<td>O</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Encounters</td>
<td>O</td>
</tr>
</tbody>
</table>

**Table 02: Mapping**

**Used By:**
- Consultation Note (optional)
- Discharge Summary (optional)
- History and Physical (required)
- Procedure Note (optional)

**Can be grouped together, only difference is the date**

**Text only**

**Not equivalent in regular specification**

CCD, can add an open template, not included

**4 sections not present in epSOS PS**
Comparison of EHR summaries and the International Patient Summary bottom line

- Same base Standard (HL7 CDA)
- Different philosophy: capture vs continuity of care
- Different IGs: C-CDA/CCD (US realm) vs epSOS IG
- Different technical approach: Open vs Closed Template
Syntactic Mapping

XSLT transformation for the value data elements

Can range from very simple (only changing the template ID) to complex (change template ID, change structure, map from two possible ways of expressing a data element to one or vice versa).

7.1.2.4  Preferred HCP/Legal Organization Country

7.1.2.4.1  epSOS and CCD XPaths for This Data Element

epSOS:

/ClinicalDocument[templateId/@root="1.3.6.1.4.1.19376.1.5.3.1.2.3"]/participant/associatedEntity/addr/country

OR

/ClinicalDocument[templateId/@root="1.3.6.1.4.1.19376.1.5.3.1.2.3"]/participant/associatedEntity/scopingOrganization/addr/country

CCD:

/ClinicalDocument[templateId/@root="2.16.840.1.113883.10.20.22.1.2"]/participant/associatedEntity/addr/country

7.1.2.4.2  Functional Requirements for the Transformer

FRT07 - The transformation will have to change the template ID and the structure from epSOS to CCD for the data element Country (Preferred HCP/Legal Organization Country) as per the Xpaths. Please note that there are two possibilities to express the preferred HCP in epSOS as it is seen a point of contact for the patient. They both need to be mapped to the same element in CCD. The mapping providing a common vocabulary for the value of this data element from the CTS2 server is listed in section 7.1.2.8.

FRT08 - The transformation will have to change the template ID and the structure of the CCD to epSOS for the data element Country (Preferred HCP/Legal Organization Country) as per the Xpaths. Please note that there are two possible ways in which the preferred HCP can be expressed in epSOS as it is seen point of contact for the patient. The CCD structure needs to map to both way of expression. The mapping providing a common vocabulary for the value of this data element from the CTS2 server is listed in section 7.1.2.8.
### Statistics: Coding systems and Value sets

<table>
<thead>
<tr>
<th>22 Code Systems</th>
<th>25 CCD value sets (of 65)</th>
<th>26 epSOS value sets (of 46)</th>
</tr>
</thead>
<tbody>
<tr>
<td>ATC</td>
<td>CCD_HITSP Vital Sign Result Type</td>
<td>epSOSActiveIngredient</td>
</tr>
<tr>
<td>CVX</td>
<td>CCD_Administrative Gender (HL7)</td>
<td>epSOSAdministrativeGender</td>
</tr>
<tr>
<td>EDQM Standard Terms</td>
<td>CCD_AgePQ_UCUM</td>
<td>epSOSAdverseEventType</td>
</tr>
<tr>
<td>HL7 AddressUse</td>
<td>CCD_Allergy/Adverse Event Type</td>
<td>epSOSAllergenNoDrugs</td>
</tr>
<tr>
<td>HL7 AdministrativeGender</td>
<td>CCD_CountryValueSet</td>
<td>epSOSBloodGroup</td>
</tr>
<tr>
<td>HL7 Confidentiality</td>
<td>CCD_EntityNamePartQualifier</td>
<td>epSOSBloodPressure</td>
</tr>
<tr>
<td>HL7 RoleClass</td>
<td>CCD_HL7 BasicConfidentialityKind</td>
<td>epSOSCodeProb</td>
</tr>
<tr>
<td>HL7 RoleCode</td>
<td>CCD_INDRoleclassCodes</td>
<td>epSOSConfidentiality</td>
</tr>
<tr>
<td>ICD-10</td>
<td>CCD_BirthStatus</td>
<td>epSOSCountry</td>
</tr>
<tr>
<td>ICD-10-CM</td>
<td>CCD_BirthStatus</td>
<td>epSOSDoseForm</td>
</tr>
<tr>
<td>ISCO-08</td>
<td>CCD_BirthStatus</td>
<td>epSOSEntityNamePartQualifier</td>
</tr>
<tr>
<td>ISO 3166-1 Country Codes</td>
<td>CCD_BirthStatus</td>
<td>epSOSHealthcareProfessionalRoles</td>
</tr>
<tr>
<td>ISO 639-1</td>
<td>CCD_BirthStatus</td>
<td>epSOLanguage</td>
</tr>
<tr>
<td>LOINC</td>
<td>CCD_BirthStatus</td>
<td>epSOSMedicalDevices</td>
</tr>
<tr>
<td>NCI Thesaurus</td>
<td>CCD_BirthStatus</td>
<td>epSOSPersonalRelationship</td>
</tr>
<tr>
<td>NDF-RT</td>
<td>CCD_BirthStatus</td>
<td>epSOSPregnancyInformation</td>
</tr>
<tr>
<td>NUCC</td>
<td>CCD_BirthStatus</td>
<td>epSOSProcedures</td>
</tr>
<tr>
<td>RxNorm</td>
<td>CCD_BirthStatus</td>
<td>epSOSReactionAllergy</td>
</tr>
<tr>
<td>SNOMED CT</td>
<td>CCD_BirthStatus</td>
<td>epSOSResolutionOutcome</td>
</tr>
<tr>
<td>SNOMED CT</td>
<td>CCD_BirthStatus</td>
<td>epSOSRoleClass</td>
</tr>
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<td>SNUMED CT</td>
<td>CCD_BirthStatus</td>
<td>epSOSRouteofAdministration</td>
</tr>
<tr>
<td>SNOMED CT</td>
<td>CCD_BirthStatus</td>
<td>epSOSSocialHistory</td>
</tr>
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<td>CCD_BirthStatus</td>
<td>epSOSStatusCode</td>
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<td>UNII</td>
<td>CCD_BirthStatus</td>
<td>epSOSTelecomAddress</td>
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<td>epSOSUnits</td>
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<td>CCD_BirthStatus</td>
<td>epSOSVaccine</td>
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</table>

<table>
<thead>
<tr>
<th>19 Association or Mappings</th>
</tr>
</thead>
<tbody>
<tr>
<td>ATC_NDF-RT_epSOSActiveIngredient_VS</td>
</tr>
<tr>
<td>ATC_RxNorm_epSOSActiveIngredient_VS</td>
</tr>
<tr>
<td>CVX_SNOMED CT_Vaccine Administered_VS</td>
</tr>
<tr>
<td>EDQM_NCI_epSOSDoseForm_VS</td>
</tr>
<tr>
<td>EDQM_NCI_epSOSRouteofAdministration_VS</td>
</tr>
<tr>
<td>ICD 10 CM_SNOMED_CT_epSOSIllnesses_VS</td>
</tr>
<tr>
<td>ICD 10_SNOMED CT_epSOSIllnesses_VS</td>
</tr>
<tr>
<td>ISCO_NUCC_epSOSHealthcareProfessionalRoles_VS</td>
</tr>
<tr>
<td>NCI_EDQM_Medication Product Form_VS</td>
</tr>
<tr>
<td>NCI_EDQM_Medication Route FDA_VS</td>
</tr>
<tr>
<td>NDF-RT_ATC_Drug_Class_VS</td>
</tr>
<tr>
<td>NUCC_ISCO_ProviderType_VS</td>
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<td>RxNorm_ATC_Clinical_Drug_VS</td>
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<td>RxNorm_ATC_Medication Brand_VS</td>
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<td>SNOMED CT_CVX_epSOSVaccine_VS</td>
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<td>SNOMED CT_to_ICD 10 CM_CCD_Problem_VS</td>
</tr>
<tr>
<td>SNOMED CT_to_ICD 10_CCD_Problem_VS</td>
</tr>
<tr>
<td>SNOMED CT_UNII_epSOSAllergenNoDrugs_VS</td>
</tr>
<tr>
<td>UNII_to_SNOMED_CT_IngredientName_VS</td>
</tr>
</tbody>
</table>
Value Sets Mapping: 
the case of SNOMED CT to ICD-10

- Official mapping in uni-directional (SNOMED CT-ICD10), the reverse does not exist

- The official map was used in reverse to get the mapping ICD-10-SNOMED CT

- Initially we wanted to look at one-to-one, many-to-one and one-to-many mappings

- It quickly became evident that the one-to-many mappings must be excluded as it introduces ambiguity (which term to choose to send? All? If receiving 4 terms, which one is the correct one?)

- Synonyms were counted only once

- Stringent rules were chosen in the mapping of SNOMED CT

<table>
<thead>
<tr>
<th>SNOMED CT code</th>
<th>SNOMED CT designation</th>
<th>ICD-10-CM code</th>
<th>ICD-10 designation</th>
</tr>
</thead>
<tbody>
<tr>
<td>193003</td>
<td>Benign hypertensive renal disease</td>
<td>112.9</td>
<td>Hypertensive renal disease without renal failure</td>
</tr>
<tr>
<td>193003</td>
<td>Benign hypertensive renal disease</td>
<td>N18.9</td>
<td>Chronic kidney disease, unspecified</td>
</tr>
<tr>
<td>2355008</td>
<td>Rud Syndrome</td>
<td>Q80.3</td>
<td>Congenital bullous ichthyosiform erythroderma</td>
</tr>
<tr>
<td>2355008</td>
<td>Rud Syndrome</td>
<td>F79</td>
<td>Unspecified intellectual disabilities</td>
</tr>
<tr>
<td>2355008</td>
<td>Rud Syndrome</td>
<td>Q87.1</td>
<td>Congenital malform syndromes predom assoc w short stature</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>ICD-10-CM code</th>
<th>ICD-10-CM designation</th>
<th>SNOMED CT code</th>
<th>SNOMED CT designation</th>
</tr>
</thead>
<tbody>
<tr>
<td>A00.9</td>
<td>Cholera, unspecified</td>
<td>63650001</td>
<td>Cholera</td>
</tr>
<tr>
<td>A00.9</td>
<td>Cholera, unspecified</td>
<td>240350003</td>
<td>Cholera - non-O1 group vibrio</td>
</tr>
<tr>
<td>A00.9</td>
<td>Cholera, unspecified</td>
<td>240351004</td>
<td>Cholera - O139 group Vibrio cholerae</td>
</tr>
<tr>
<td>A00.9</td>
<td>Cholera, unspecified</td>
<td>446672004</td>
<td>Intestinal infection due to Vibrio cholerae non-O139</td>
</tr>
<tr>
<td>A00.9</td>
<td>Cholera, unspecified</td>
<td>447282003</td>
<td>Intestinal infection due to Vibrio cholerae O1</td>
</tr>
</tbody>
</table>
Use Case: Patient Mediated Scenario
Patient Mediated Scenario
High level Architecture

- Extension of US Blue-Button / epSOS Patient Access
- Documents are retrieved by the patient and taken abroad by her/him
- Return of information can be handled by the patient, too
- Opens new scenarios on cross-border liability
- Might put the roots for changing epSOS cross border paradigms:
  - Transformation in Country of Origin / Translation in Country of treatments
Provider Mediated Logical View
It extends the B2B epSOS architecture adding a new node with a super element which acts on one side as US eHealth Exchange and on the other side as an NCP.

Into it the “Transformer” is embedded.
Is Bridging patient summaries across the Atlantic feasible?

Made first steps

- original code is always be sent for safety reasons
- original document is always available in its entirety

Sustainable Mapping in need of rigorous sustainable QA process by subject matter experts

- a way to aggregate and join efforts into renewable interoperability assets
- Crowd sourcing

Interoperability assets (mapping of terminologies and structures) and a common baseline for the International patient summary

Terminology Assets present in the CTS2-based terminology server: http://extension.phast.fr/STS_UI/
The “Trillium” Team: believers, builders, entrepreneurs

EU Member States
Entrepreneurs
US Health Care Providers
Standards Developing Organizations

Supported by
Kaiser Permanente
Atrius Health Foundation
Lantana
smartphr.
Looking into the future: Large scale eHealth Deployment
EXPAND: Consolidate eHealth Assets
Hand over to Connecting Europe Facility

The Maintenance Shops

Legal & Organizational
Specifications
Semantic
Technical
Testing
Deployment
Operations

With Trillium Bridge:

• Adopt epSOS NCP infrastructure to include EU/US Transformer
• Extend epSOS Patient Access for the new paradigm of Patient Mediated
• Analyse gaps (IHE profiles, HL7 CDA, Terminologies) to enhance harmonization and interoperability
Four interlinked projects ~4M€ total funding:

- **OpenMedicine** (1/1/2015 - 31/12/16)
  - What do we do with medication (for ePrescription/eDepensation)
  - Assess adoption of ISO IDMP, in co-operation with EMA, Agencies, MoH
  - Exploiting pharmacovigilance database

- **ASSESS-CT** (1/2/2015 - 31/1/16)
  - What do we do with Terminologies and SNOMED CT?
  - HL7 Foundation will run country focus groups and deliver on the current use and future potential of SNOMED CT

- **eStandards** (1/5/2015 - 30/4/17)
  - What do we do with standards and profiles?
  - HL7 Foundation is the scientific lead aiming to rethink ISO/CEN standards and profiles e.g. IHE, Continua for large scale deployment

- **VALUeHEALTH** (1/4/2015 - 31/3/17)
  - What are the business case and business models and innovation for standards?
  - Provide sustainability until 2020 (CEF) and beyond
Conclusions

- **HL7 with support from other SDOs focuses on an international patient summary specification**
  - Allergies, problems, medication

- **Likelihood of convergence towards a single standard for patient summaries is low**
  - Build, maintain, and Quality assure Mappings
  - Adopt FHIR resources
  - rethink interoperability and standards

- **Europe is heading for large scale eHealth deployment**
  - Four projects to support practical eHealth interoperability
  - Hope is that global, European, national, local efforts are convergent to increase the effectiveness and impact of health Information technology

- For HL7 this means pursuing its 25 year mission
  “to create the best and most widely used standards in health care”
Building Bridges
to make dreams come true

HAPPY ARE THOSE WHO DREAM
DREAMS AND ARE WILLING TO
SACRIFICE TO MAKE THEM COME
TRUE.

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