Bridging patient summaries across the Atlantic

Catherine Chronaki, Robert H. Dolin, Marcello Melgara, Harold Solbrig, Jamie Ferguson, Dipak Kalra

www.trilliumbridge.eu

coming soon…
Structure and aims for today’s workshop

**Objectives**
- Briefly present the Trillium Bridge project
- Discuss use cases of transatlantic exchange of patient summaries
- Identify issues, interoperability assets and opportunities
- Recognize barriers and strategies to overcome them
- Engage the health informatics community as part of the solution

**Structure**
- Four presentations
- Structured Discussion
- Collection of questionnaires
- Findings and next steps
The Speakers

Catherine Chronaki
- HL7 Foundation, coordinator of Trillium Bridge support action
- Introduction to Trillium Bridge
- Selecting the Grounds: Supporting EU/US initiatives & use cases

Harold Solbrig
- Mayo Clinic, co-leader of the Interoperability assets work package
  (Building the Bridge)
- Building the Bridge: Interoperability assets

Dipak Kalra
- Eurorec, Coordinator Semantic Healthnet, Leader Policy alignment, Standardization, Future sustainability Work package in Trillium Bridge
- Policy alignment
- The case of heart failure: “are we talking about the same disease?”

Jamie Ferguson
- Kaiser Permanente, VP Health Information Technology Strategy & Policy
- The case of medication allergy avoidance
Bridging patient summaries across the Atlantic: Your input!

Q1: What are the compelling use cases for the transatlantic sharing of personal health information?

Q2: What are the critical success factors to enable the Trillium Bridge project to succeed?

Q3: What key barriers will Trillium Bridge need to address?

Q4: Are there other important initiatives that we need to know about or liaise with?

Q5: Which ONEs do you see as most important areas for investment in bridging patient summaries across the Atlantic?

- Cross-vendor integration
- Incentives
- Standardization
- Innovative Business models
- Education
- Clinical Research
- Security and privacy
Policy context or what’s in a name?

Ensure **sustainability** of the healthcare system

Unlock the **market** for innovation

Deliver Quality Care - better care
Objectives of Trillium Bridge

- Build a bridge for EU/US patient summaries across the Atlantic
  - Identify use cases of transatlantic exchange of patient summaries
  - Compile gap analysis to identify barriers and easy wins
  - Assemble Interoperability assets to support implementation
  - Validate exchange of patient summaries
  - Facilitate policy alignment, future standardization, and sustainability
  - Develop feasibility study to guide future developments

Why?

- Lower costs/barriers for transatlantic business engagement
- Reduce implementation/configuration costs
- Decrease standards development costs
- Accelerate convergence towards global standards
- Support the fundamental right of citizens to their health information

First steps towards realizing the vision and implementing the Roadmap of the EU-US MoU on eHealth/Health IT cooperation
Milestones to success

Selecting the Grounds:
- Pilot Use Cases
- Business Architecture
- Gap Analysis

Building the Bridge:
- Aligning Structure & Terminology
- Trust Agreements
- Interoperability assets

Testing the Bridge:
- Testing Tools, Data Sets
- Validation Reports

Policy Alignment:
- eIdentification, Security & Privacy
- Legal / Regulatory Interoperability
- Feasibility Analysis
- Cross-vendor integration
- Incentives
- Standardization
- Innovative Business models
- Education
- Clinical Research
- Security and privacy
Patient-driven questions and needs

- **EU citizen going to the US**
  - How can European citizens or residents request and receive their epSOS patient summary and, with their consent, have it delivered to a cloud service or health app that would translate it to a form that can be understood, trusted, and incorporated in the EHR of a US provider?

- **EU citizens receiving care in the US**
  - How can European Citizens or residents receiving the services of a US provider while travelling in the US, have a care summary delivered to them or safely uploaded into a PHR or provider’s portal in a format that is compatible with epSOS?

- **US citizens going to Europe**
  - How can members of US-based health networks receive an MU-2 certified care summary in a format and language that epSOS providers will be able to understand and use?

- **US citizens receiving care in the EU**
  - How can members of US-based health networks, upon receiving the services of an epSOS provider translate and transfer the encounter report to the EHR system of US providers?
Who is part of Trillium Bridge?

Community of knowledge, interoperability assets, policy alignment
EU/US Community of Knowledge

**Providers**
- Beth Israel Deaconess MC, US
- University Hospitals Genève, CH
- Duke Center Health Informatics, US

**National programs**
- NHS - Connecting for Health, UK
- Agence eSanté Luxemburg, LU
- French Ministry of Health, FR
- Spanish Ministry of Health, ES
- MedCom, Dk
- KELA, Fi

**European Federation for Medical Informatics (EFMI)**
- Travel EHR initiative (IMIA)

**European Patients Forum**

**Validation sites**
- Kaiser Permanente, US
- Italian Ministry of Health, IT & Lombardia
- Atrius Health, US
- Slovenia, SI
- Portuguese Ministry of Health, Pt

**Industry**
- Indizen, Spain
- IBM research labs, Il
- CISCO
- Marand, Slovenia

**Marketplace**
- ECHAlliance and the EU-US Marketplace

**SDO advisory forum**
- IHTSDO, GS1, CDISC, CEN, NEN, EN13606 Association, Health Story
Bridging patient summaries across the Atlantic
European Perspective based on epSOS

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epSOS in Pils

epSOS Consortium is composed by **48 beneficiaries** from **26 States**:
Austria, Belgium, Croatia, Czech rep., Denmark, Estonia, Finland, France, Greece, Hungary, Germany, Italy, Latvia, Luxembourg, Malta, Netherland, Norway, Poland, Portugal, Slovakia, Slovenia, Spain, Sweden, Switzerland, United Kingdom, Turkey

+ **Industry Team (~45)**

15 Observers: Bulgaria, Iceland, Lithuania, Serbia,, ... + USA, Canada = Total **40+ Nations**

– Coordinator: **SALAR** (Swedish Association of Local Authorities and Regions)

– **From 01.07.2008 to 31.12.2013**
(6 month extension under discussion)
Goals and Challenges

In preparation and application of:
- EU Directive on Patient Cross-border Mobility (April 2011)

Goal for the epSOS eHealth Project:
- “to develop a practical eHealth framework and ICT infrastructure [based on existing national infrastructures] that will enable secure access to patient health information, particularly with respect to a basic patient summary and ePrescription, between European health care systems”
- To define normative specifications for EU level cross border interoperability
- Without interfering with National/Regional policies, strategies and implementation of National/Regional EHR / PHR (e.g. no specs on how EHR/PHR is managed, or documents returned from the Country of treatment are handled)

Challenges to get there: harmonize 26 Health Care systems
- Legal Interoperability
- Organisational Interoperability
- Semantic Interoperability
- Technical Interoperability
epSOS Use Cases

Patient Summary (PS):
- while abroad, a patient seeks unexpected care. The Health Professional, after having identified and checked the consent confirmation, requests the PS from the Country of Affiliation. The PS is shown mapped in the epSOS pivot format, with coded data translated in Country of Treatment language.

Health Care Encounter Report (HCER):
- while abroad, a patient seeks unexpected care. The Health Professional, after having received the PS, generates a CDA L3 document as Encounter Report. The document is transferred, mapped and translated to the Country of Affiliation.

Medication Related Overview (MRO):
- A pharmacist, who cannot access the PS, requests the medication summary and list of allergies (frequently derived from the PS).

Patient Access:
- A patient while in the Country of Affiliation, may request his PS mapped and translated in one of the epSOS languages.

This is the basis for Trillium Bridge Patient Mediated Interoperability.
What epSOS Patient Summary is

- **A clinical document**
  - with medical/legal value, to assure continuity of care for unexpected/ emergency situations

- **Requested**
  - by the physician, after patient authorization

- **Generated**
  - by the National Contact Point (NCP) of Country of affiliation as a structured and coded HL7 CDA V2 L3 document. Original PS is transferred as PDF embedded in a CDA V2 L1 document

- **Translated**
  - in the local language by the NCP of the Country of Treatment

- **Visualized**
  - by the physician using a specific CDA display tool

- **The Healthcare Encounter Report (HCER), with the same structure, can be generated and returned to the Country of Affiliation**
What epSOS Patient Summary is:

- A team of clinical experts from epSOS Countries defined the contents of the PS, according to:
  - Relevance to cope with unexpected/emergency situations
  - Availability of (coded) information in the EU Country PS’s
  - Compliance to CCD /PCC and CDA V2 L3 specifications

- Basic mandatory sections are:
  - Header info to identify the patient, date & document creator, PS nature
  - Allergies and medical alerts
  - Active problems
  - Recent surgical procedures
  - List of current medicines (posology is optional)
  - Medical devices and implants

- Patient data, document creator data, creation date cannot be Null
- Basic clinical info sections must be present, but null flavor is allowed
What epSOS Patient Summary is:

Extended optional sections are:
- Header: Insurance information, contact info/persons/institutions
- Vaccinations
- Resolved problems
- Surgical procedures, not older than 6 months
- Treatment recommendations
- Autonomy/Invalidity
- Social history observations (smoke, alcohol,..)
- Pregnancy /date of expected delivery
- Physical findings. Vital signs - blood pressure (only)
- Diagnostic tests. Blood group (only)

Extended sections can be omitted, if not relevant
What epSOS PS is: terminology

For each section/subsection a standard coding system is identified

A specific Value Set allows transcoding and translation

<table>
<thead>
<tr>
<th>FIELD</th>
<th>TERMINOLOGY CHOSEN</th>
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</thead>
<tbody>
<tr>
<td>Field Labels</td>
<td>LOINC</td>
</tr>
<tr>
<td>Problem list</td>
<td>ICD 10 (3 digit code)</td>
</tr>
<tr>
<td>Medication list</td>
<td>ATC + EDQM + UCUM</td>
</tr>
<tr>
<td>Allergies</td>
<td>SNOMED</td>
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<tr>
<td>Surgical procedures</td>
<td>SNOMED</td>
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<tr>
<td>Medical devices</td>
<td>SNOMED</td>
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<tr>
<td>Country and languages</td>
<td>ISO</td>
</tr>
<tr>
<td>Professional role</td>
<td>ISCO</td>
</tr>
</tbody>
</table>
What epSOS PS is not:

- Hospital discharge letter
- Detailed document for specialist second opinion request
- Pathology specific / rare disease medical reports

Why?

- Missing non-surgical procedures
- Laboratory test results
- Limited details in describing problems

When limits will be overcome?

- epSOS is evaluating the adoption of the full ICD10
- Extensions of the Value Sets and introduction of new sections is in the scope of CIP/PSP Expand Project (2014-2016).
epSOS Use Cases

How the document is transformed into Pivot HL7 CDA L3, trascoded and translated

Local document A is coded with ICD-10 4-digit codes and sent to NCP A

Transformation ICD-10 4-digit to 3-digits codes
Accession to epSOS Terminology Server A
Translation of displayName A to displayName E
Creation of pivot Document E*

Accession to epSOS Terminology Server B
Translation of displayName E to displayName B
Creation of local Document B*

Local document A is coded with ICD-10 4-digit codes and sent to NCP A

CDA Language A
ICD-10 4-digits codes
Or ICD-9

CDA Language B
ICD-10 3-digits codes

epSOS Central Reference Terminology Service:
Master Value Set Catalogue: [MVC,]
Subset of International Coding Systems (WHO ICD10, ATC; SNOMED-CT, EDQM, UCUM, HL7, IHE, ISCO)+
Master Translation/Transcoding Catalogue [MTC]
epSOS setting sails

- **First dispensation:** eP Lombardy: Athens 11/2011
- **Pilots with real patients (since 4/2012):**
  - PS: AT, CH, ES, FR, IT, PT, (CZ)
  - eP: IT (Country A), GR (Country B)
- **Next PNs ready to pilot:**
  - PS: EE, MT, SI
  - eP: DK, ES, FI, SE
- **PNs in Pre-Production Testing:**
  - PS: HU, LU, DE*, TR*
  - eP: HU, HR

(*: legal constraints)
From epSOS Patient Access (PAC) to Trillium Bridge services

Some epSOS Countries plan to provide their citizens with epSOS Patient Access Service:

- The citizen may request his PS, in epSOS format, translated into any epSOS language

Trillium will extend the service by providing the export in the selected format to allow:

- Patient mediated access:
  - English document handed/showed to the US physician
  - Structured document provided through secure media/mail/clouds

- Provider mediated access:
  - The US physician requests the document to the EU healthcare institution (more difficult to implement)

- Providing ways of importing TO EU citizen PHR/EHR PS generated in US
- Providing services to EU physician to read/access to US citizen PS
Bridging Patient Summaries across the Atlantic
US perspective

Bob Dolin
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Consolidated CDA

Overview of Meaningful Use

Overview of Consolidated CDA

Consolidated CDA Use Cases

Trillium Bridge Considerations
Overview of MU2

Meaningful Use Stage 2 sets “criteria” for EHRs

EHRs meeting those criteria are MU2-certified

Providers using certified EHRs are eligible for incentive payments
# CDA in MU2

<table>
<thead>
<tr>
<th>§ 170.205</th>
<th>Content exchange standards and implementation specifications for exchanging electronic health information.</th>
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</thead>
<tbody>
<tr>
<td>170.205(h)</td>
<td>CDA Guide for Quality Reporting Document Architecture, Category I (QRDA-I): Standardized representation of quality data for an individual patient. Data in a QRDA-I report can be consumed by a calculation engine to determine if the patient met the numerator or denominator criteria for a given quality measure.</td>
</tr>
<tr>
<td>170.205(i)</td>
<td>CDA Guide for Reporting to Central Cancer Registries: Standardized cancer registry reporting format.</td>
</tr>
<tr>
<td>170.205(k)</td>
<td>CDA Guide for Quality Reporting Document Architecture, Category III (QRDA-III): Standardized representation of aggregate quality data (e.g. number of patients meeting the numerator criteria for a given quality measure).</td>
</tr>
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</table>
Consolidated CDA

Many different kinds of documents:
- CCD
- Consultation Note
- Diagnostic Imaging Report
- Discharge Summary
- H&P
- Operative Note
- Procedure Note
- Progress Note
- Unstructured Document

A bucket of reusable templates
CCD (Summary Document)

Sections
- Payers
- Advance Directives
- Support
- Functional Status
- Problems (R)
- Family History
- Social History
- Allergies (R)
- Medications (R)
- Medical Equipment
- Immunizations
- Vital Signs
- Results (R)
- Procedures (R)
- Encounters
- Plan of Care
Consolidated CDA Use Cases

- **Narrative Interoperability**
  - Basic CDA functionality

- **3rd Party Data Aggregation**
  - E.g. registry

- **Data Integration**
  - HARD
  - Often achieved via clinician-assisted data reconciliation
Trillium Bridge Considerations

“Harmonization” and “Internationalization” (as opposed to “Transformation”)

- Vendors want global standards
- Decrease standards development effort
- Decrease realm localization requirements
- Mapping is HARD, and not sustainable
# Trillium Bridge Considerations

## Compare data structures

- Sections, CDA entry-level templates

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<td>Social History</td>
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# Trillium Bridge Considerations

## Compare vocabularies

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Copenhagen
Aug 21, 2013
Summary

Trillium Bridge will carry out a feasibility study with validation reports of EU/US Patient summary exchange, reusable interoperability assets and policy work to:

- Lower costs/barriers for transatlantic business engagement
- Reduce implementation/configuration costs
- Decrease standards development costs
- Accelerate convergence towards global standards

That would be concrete steps towards realizing the EU/US MoU vision for transatlantic cooperation “to improve patient health and health care delivery, enable economic growth and nurture innovation.”
Why don’t you join us to build the Trillium Bridge?
http://es.surveymonkey.com/s/6VXQFQ2
Trillium Bridge:  
Mapping Terminologies and CTS2

Solbrig.harold@mayo.edu  
Skype: hsolbrig
Outline

• Description of the task
• Why terminology services?
• Why CTS2?
Outline

• **Description of the task**
• Why terminology services?
• Why CTS2?
epSOS Use Cases

The document is transformed into Pivot HL7 CDA L3, trascoded and translated

Local document A is coded with ICD-10 4-digit codes and sent to NCP A

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epSOS Central Reference Terminology Service:
Master Value Set Catalogue: [MVC,]
Subset of International Coding Systems (WHO ICD10, ATC; SNOMED-CT, EDQM, UCUM, HL7, IHE, ISCO)+
Master Translation/Transcoding Catalogue [MTC]
epSOS Use Cases

Additional Transformations - Putting a Local Document into CDA and Transforming it back to a Local System

- Local document A is coded with ICD-10 4-digit codes and sent to NCP A
- Transformation ICD-10 4-digit to 3-digits codes
  - Accession to epSOS Terminology Server A
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Outline

• Description of the task
• Why terminology services?
• Why CTS2?
Transform Generation Requires Services

- Upload Local Value Sets / Terminology
- Upload Meaningful Use / epSOS Value Sets
- Create / Edit / Validate Transformations
- Transform Mappings to Target Services
Transformation Maintenance Requires Services

- Subscribe to new value sets / new versions
- Publish new local sets
- Update maps
- Validation / Identification / Workflow
Is This Scalable?

Yes, but only if you agree on a single data model / service api / workflow.

• The task is plenty big without...
  – Different formats for different terminologies
  – Different mapping tools and API’s
  – Different translation / mapping services
Outline

• Description of the task
• Why terminology services?
• Why CTS2?
HL7 / Object Management Group Standard

• Focus is ‘Terminological Resources’
  – Code Systems / Value Set Definitions / Resolved Value Sets / Map Definitions / Map Access
  – Resource Oriented Architecture (ROA)
    • Federation
    • Distribution
    • Identification
  – Supports Read / Query / Import / Update
  – Supports multiple versions
CTS2

**CTS2 SFM** – Service Functional Model.

- *Requirements* for a terminology services.
- DSTU (2009)

**CTS2 1.0** – Official OMG Standard, published in November 2013

**CTS2N** – CTS2 “Normative”

- HL7 follow on document defining CTS2 conformance profiles in terms of SFM
- Still being balloted
Healthcare Services Specification Project (HSSP) Timeline

- **HL7**: SFM → CTS2 N
- **OMG**: RFP → Beta Standard → CTS 1.0 Standard
- **Vendor Community**: Proposed Standard → Corrections / Clarifications

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CTS2 Standard as a Blueprint

CTS2 Clients

CTS2 Services
CTS2
Implementations and Uptake

• PHAST STS Server
• BioPortal REST
• BioPortal RDF
• SNOMED CT Implementation Guide Demo
  http://informatics.mayo.edu/cts2/services/sct/cts2/
• Meaningful Use VS Service (VSMC) https://informatics.mayo.edu/vsmc/
• SHARP VS Service
  http://informatics.mayo.edu/cts2/services/sharp/viewer/?showAll=true
• Indizen ItServer http://www.itserver.es/ITServer/
CTS2
Projects Underway

• UMLS CTS2 Server
  – Building on underlying UMLS Meme SQL Tables

• HL7 MIF Vocabulary
  – Alpha Transformation written
  – Will validate w/ HL7
  – Should become basis of HL7 IG

• “TLAMP”
  – SNOMED CT/ICD-9-CM/ICD-10-CM/LOINC/HL7/RxNorm
  – Looking at “close to source”
CTS2 Directions

- MDHT / CTS2 / 11179 integration (!)
- CIMI Terminology Services
- ICD-11 CTS2 server
- CTS2 OWL Implementation Guide (via W3C)
- PHIN Vads wrapper
- Mapping pipeline using ItServer
Summary

• Semantics - Trillium Bridge project will evaluate what can be done today and what more needs to be done
• Focus must be on semantics, not technology
• CTS2 specification and implementations provide a technological foundation for the project.
Trillium Bridge
Putting Patient Summaries To Work:
A Practical Perspective

jamie.ferguson@kp.org
Putting Patient Summaries To Work
A Practical Perspective

1. Practical Use Case Scenario Implementation
   – About Exchange Modalities
   – Provider Mediated Exchange
   – Patient Mediated Exchange

2. Case Example: Medication Allergy Avoidance

3. A Framework For Evaluating Project Efforts
About Exchange Modalities

• US Direct Email
  – Specifications: ONC XDR, XDM; IETF SMTP, S/MIME

• US eHealth Exchange
  – Specifications based on: IHE XDS, XCA, XDR, XCPD, PIX/PDQ, ATNA; OASIS SAML, XSPA; W3C MTOM and others

• EU epSOS
  – Specifications based on: IHE XDS, XCA, XDR, XCPD, PIX/PDQ, ATNA; OASIS SAML, XSPA; W3C MTOM and others
Provider Implementation Architecture

US Provider Mediated Exchange

XDR PERSISTENCE
- RIMBAA
- RMDBS
- DOCUMENTS/BINARY FILES

INTERNAL IT SERVICES
- EMR SYSTEM
- OTHER SYSTEMS

CLINICAL GRAPHICAL TOOLS

CLINICAL VOCABULARY SERVICES

GATEWAY

HEALTH CARE ENTITY

HEALTH CARE ENTITY
Provider Implementation Architecture
Multiple Exchange Modalities

PATIENT SUPPLIED INFO.

XDR PERSISTENCE
- RIMBAA
- RMDBS
- DOCUMENTS/BINARY FILES

EMR SYSTEM
- OTHER SYSTEMS

CLINICAL GRAPHICAL TOOLS

INTERNAL IT SERVICES

CLINICAL VOCABULARY SERVICES

GATEWAY

HEALTH CARE ENTITY

CLOUD SVCS

HEALTH CARE ENTITY

25 August 2013
Trillium Bridge at MEDINFO 2013
A Real Case Example
Date: Fourth Quarter, 2009

- A military veteran patient presented for a medical visit at Kaiser Permanente.
- He neglected to mention the occurrence of two new life-threatening allergic reactions that had recently been documented at the VA Medical Center.
- We queried his CCD summary record through the eHealth Exchange from VA.
- His physician was instantly able to see those two medication allergies.
- One allergy was to a statin and the other an anti-hypertensive.
- The patient's last cholesterol and current blood pressure were not well-controlled, therefore it would have been easy to prescribe a drug in the same class of medications as the recently defined allergies, which may have resulted in a life-threatening event.
- Instant availability of the HL7 CDA information via XDS-based exchange was critical to proper decision-making and may have saved this patient's life.
A Framework For Assessment
1 of 2

Principles of the Global Health Data Charter provide direction on the journey

1. **Availability:** Health data should be made available for authorized uses.
2. **Accessibility:** Individuals and other users of health data should know what data exists and how to access it.
3. **Data Quality:** Data quality and integrity must be maintained throughout the life of health data.
4. **Standardization:** Common health data standards must be adopted to facilitate comparability and interoperability.
5. **Technology:** Digital records, interoperable networks and technical toolsets must be in place for optimal management and dissemination of health data.
6. **Rights & Protection:** Clear policies should be implemented to assure the privacy and security of health data.
7. **Re-Use:** Appropriately de-identified health data should be used to advance research, public health, quality improvement and other efforts.
8. **Stewardship:** Clear accountabilities for managing, using, and protecting health data, should be established to build confidence and promote data-sharing.
Enablers for successful implementation

1. **Leadership:** Appropriate leadership must create the necessary cultural change.
2. **Collaboration:** Cooperation and collaboration must be mobilized to realize benefits.
3. **Capacity:** Targeted efforts to build capacity must be implemented to ensure that the requisite knowledge, skills, infrastructure, processes and technology are in place.
4. **Knowledge:** Stakeholders must actively collect, organize and disseminate best practices, lessons learned, case studies, etc. for health data and informed decision-making.
5. **Investment:** Sufficient financial and other resources must be mobilized to support the necessary effort to both launch and sustain implementation.
6. **Incentives:** Appropriate incentives must be put in place to expedite adoption.
7. **Evaluation:** A systematic, standardized global approach to measuring adoption of agreed principles must be implemented to assess and accelerate improvement.

Expectations

- Patient Mediated Exchange Is Practical Today!

- Semantics and exchange technology must be evaluated and developed together to have any practical effect

- Transatlantic harmonization of XDS-based exchange is possible but difficult

- Innovative cloud exchange services are promising
Questions?

Trillium Bridge:
Bridging Patient Summaries across the Atlantic

jamie.ferguson@kp.org
An interoperable heart failure summary: transatlantic policy alignment and future sustainability

Dipak Kalra, EuroRec and UCL

on behalf of:
Mortality for patients hospitalised with HF

Inpatient Mortality 11.1%
- Cardiology ward 7.8%
- General medical 13.2%
- Other ward 17.4%

Source: John Cleland, Suzanna Hardman, SHN WP1
What are we trying to do, and why Heart Failure (HF)?

- Complex diagnostic, treatment and management issues
- Poor outcomes when badly managed but potential for good quality and improved expectancy, of life, when well managed
- General poor awareness in health care community and general population
- Potential for effective self management
- Care across range of domains
- Enormous capacity for miscommunication and diagnosis - dangerous
- Massive resource implications, recurrent hospitalisations, high health care contact - governments - commissioning
- Robust research basis and potential for further research

Source: John Cleland, Suzanna Hardman, SHN WP1
WP1 - Chronic heart failure patient care exemplar

• Comprised experts on Heart Failure, who

  – Specify the clinical content needed for high quality and safe integrated care for patients with CHF
  – Collaborate with the informatics experts in WP4 to develop suitable resources, and define quality criteria for them.
  – Interact and test emerging deliverables from other work-packages in an iterative fashion
  – with
    • HF Cardiologists across Europe with strategic roles
    • HF clinicians delivering HF care across Europe
    • Patients and Carers
Is it heart failure? Key information needed for diagnosis

Source: John Cleland, Suzanna Hardman, SHN WP1
The HF Information Landscape

- Death Adjudication (Only if patient dies)
- Patient Core Data
- Hospital Admissions, Discharge planning
- Medication
- Medical History First visit only
- Visits: One per contact per patient
- Physical Exam
- ECG Report
- Echocardiograph
- Blood Test results
- Questionnaire

Source: John Cleland, Suzanna Hardman, SHN WP1
Suspected heart failure caused by ischaemic heart disease

- Three heterogeneous representations of the same statement
- Three different atomic information entities

### Organ Failure Diagnosis

<table>
<thead>
<tr>
<th>Organ</th>
<th>Status</th>
<th>Caused by ischaemic heart disease</th>
</tr>
</thead>
<tbody>
<tr>
<td>Heart</td>
<td>Suspected</td>
<td>Yes</td>
</tr>
</tbody>
</table>

### Diagnosis

- Suspected heart failure caused by ischaemic heart disease

### Diagnosis

- Heart Failure
  - Status: Suspected
  - Cause: Ischaemic heart disease

Source: Stefan Schulz, Cati Martinez, SHN WP4
Standardisation, specification and profiling expertise in SHN

- Continua Health Alliance
- HL7
- IHE
- IHTSDO
- ISO EN 13606
- openEHR Foundation
- WHO

- Academic expertise: ontology, guideline representation
- Industry expertise: EHR system vendors
- Adoption, quality labelling, dissemination: EuroRec, ESC, public health
- Sustainability: EuroRec, eHGI, Ministry experts, health insurers
HL7 CDA templates

- Based on epSOS patient summary templates
- Converging with Consolidated CDA templates
- Engaging with HL7 affiliates across Europe to promote reuse of HL7 CDA templates
Interoperable representations for diagnosis: archetype, OWL DL

\[ \text{shn:DiagnosisRecord subClassOf shn:InformationItem} \]
\[ \text{and shn:hasInformationObjectAttribute some shn:CertaintyAttribute} \]
\[ \text{and btl:outcomeOf some shn:DiagnosticProcedure} \]
\[ \text{and btl:outcomeOf some (shn:Interpreting and btl:hasparticipant some shn:Evidence)} \]
\[ \text{and shn:isAboutSituation only} \]
\[ (\text{shn:ClinicalSituationX and} \]
\[ \text{and btl:temporallyRelatedTo some shn:Time} \]
\[ \text{and btl:causedBy some shn:ClinicalSituationXY}) \]
HEART FAILURE CLINIC FIRST VISIT SUMMARY

Where not otherwise stated, elements are optional ([0..1]).

<table>
<thead>
<tr>
<th>Element</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>3. Presentation and symptoms</td>
<td></td>
</tr>
<tr>
<td>4. Physical Exam</td>
<td></td>
</tr>
<tr>
<td>5. Blood tests</td>
<td></td>
</tr>
<tr>
<td>6. Electrocardiography</td>
<td></td>
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<tr>
<td>7. Echocardiography</td>
<td></td>
</tr>
<tr>
<td>8. Other non-invasive Cardiac Imaging</td>
<td></td>
</tr>
<tr>
<td>9. Lung function</td>
<td></td>
</tr>
<tr>
<td>10. Invasive investigation</td>
<td></td>
</tr>
<tr>
<td>Assessment</td>
<td></td>
</tr>
<tr>
<td>Plan</td>
<td></td>
</tr>
</tbody>
</table>

Source: Ian McNicholl, openEHR, SHN WP4
Wide scale adoption and sustainability: Trillium Bridge WP5
WP leaders: Dipak Kalra, Bob Dolin
Scope of the work on policy alignment, standardisation and sustainability

- Consider the multi-stakeholder commitments, efforts and investments that are needed to scale up the development, adoption, use and benefits realisation from transatlantic shared patient summaries.

- Consider these under seven priority topic areas (see next slide)
  - examine a range of documents and other publicly available artefacts
  - consult with the Trillium Bridge advisors and a wider range of external stakeholders, and develop a set of recommendations for each topic
  - consult via a month 12 workshop, and subsequently via online methods, in order to gain consensus on the recommendations

- Publish the final strategy brief document with an outline analysis and key recommendations for each of the topic areas, ideally as a timeline (roadmap)
Priority topic areas

- Cross-vendor integration: enable each vendor to generate and export a valid summary, and combine summaries with other data
- Education: foster the development of training for all health professional disciplines and specialties who will create or use the summary
- Privacy and security: strategies for addressing legal issues, eidentification, security and privacy protection
- Incentives: financial and non-financial incentives to encourage high levels of completeness of summaries, and for the implementation and deployment of conforming EHR systems
- Innovation: stimulation of a market in applications that capture and deliver patient summaries e.g. mobile device apps
- Future standardisation: engage SDOs in adopting the summary as a standard and interfacing it with other relevant standards
- Research: in developing other summaries for specific disease or care scenarios
DISCUSSION: for each topic area

- What are the critical success factors?
- What are the key challenges/barriers to overcome?
- What is the essential value proposition to be developed?