Trillium Bridge II – Reinforcing the Bridges and Scaling up EU/US Cooperation on Patient Summary

Coordination and Support action in EU and USA
4 standard bodies, 10+ health systems and competence centers, R&D, networks, ecosystems
Overall budget: €1104547,50 EU contribution: €1000001,25

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Brussels, 28 November, 2019
The story began with epsos...can trans-European patient summaries be understood across the Atlantic?

- **Gap analysis**
  - Compared patient summary specifications in EU/US
  - Shared clinical elements: problems, medications, allergies

- **Interoperability Assets**
  - Established a terminology prototype CTS-2 service: [http://extension.phast.fr/STS_UI](http://extension.phast.fr/STS_UI)
  - Developed Transformer of Patient summaries: [http://informatics.mayo.edu/trillium-bridge](http://informatics.mayo.edu/trillium-bridge)
  - Mediated Differences in EU/US IHE XCPD/XCA profiles for Patient Identity and Document Query/Retrieve

- **Validation activities: 4 EU countries/ Kaiser Permanente**
  - EU/US Marketplace; HIMSS 2015; IHE Europe Connectathon 2015, eHealthWeek 2014, 15

- **Feasibility study:**
  - Reflected upon standards, cross-vendor integration, incentives, clinical research, security and privacy, innovative business models, education

**Recommendation:**

"Advance an International Patient Summary (IPS) standard to enable people to access and share their health information for emergency or unplanned care anywhere and as needed. At minimum the IPS should include immunizations, allergies, medications, clinical problems, past operations and implants."
What did Trillium II for adoption of patient summaries and IPS standards?

1. Collaborate across standardization bodies
2. Contribute to Governance of IPS specifications
3. Bridge grassroots patient summary initiatives
4. Highlight the social value of patient summaries
5. Develop, Collect, Assess learning resources
6. Foster innovation & inform health policy
7. Engage mobile Health companies & app developers
8. Establish a Global IPS Community of Practice for Digital Health Innovation to build capacity
1. Collaborate across **standardization bodies**
Building blocks of IPS standards and resources

CEN/EN 17269 now up for ISO TC215 voting

**Resources made available**
data sets, information structures, value sets, tools

1. Datasets, scenarios and example value sets are available in Art-Decor:
- [https://art-decor.org/art-decor/decor-datasets--trilm2-](https://art-decor.org/art-decor/decor-datasets--trilm2-)
- [https://art-decor.org/art-decor/decor-scenarios--trilm2-](https://art-decor.org/art-decor/decor-scenarios--trilm2-)
- [https://art-decor.org/art-decor/decor-valuesets--trilm2-](https://art-decor.org/art-decor/decor-valuesets--trilm2-)

2. Source files and IPS examples are available in GitHub:
- [https://github.com/gcangioli/trilliumII](https://github.com/gcangioli/trilliumII)
- [https://github.com/gcangioli/trilliumII/tree/master/examples](https://github.com/gcangioli/trilliumII/tree/master/examples)
- [https://github.com/gcangioli/trilliumII/tree/master/IG](https://github.com/gcangioli/trilliumII/tree/master/IG)

3. FHIR Implementation Guidelines are available at HL7 or Trillium II website:
- [http://hl7.eu/fhir/build/trillium2](http://hl7.eu/fhir/build/trillium2)
- [http://hl7.eu/fhir/ig/trillium2](http://hl7.eu/fhir/ig/trillium2)
- [https://trillium2.eu/fhir/](https://trillium2.eu/fhir/)

4. FHIR servers offered by partners

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**Subject**
- PHAST

**Author**
- SPMS

**Attester**
- TicSalut

**Custodian**
- PHAST

**Medication Summary**
- THL

**Allergies & Intolerances**
- SPMS

**Problem List**
- TicSalut

**Immunizations**
- TicSalut

**History of Procedures**
- PHAST

**Medical Devices**
- TicSalut

**Vital Signs**
- THL

**History of Illness**
- Prevent3

**Pregnancy**
- Prevent3

**Social History**
- Prevent3

**Functional Status**
- Prevent3

**Advance directives**
- Prevent3

**Plan of Care**
- Prevent3

**Encounter**
- Prevent3

**Imaging**
- Prevent3

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**16th eHealth Network**

**Security & privacy**
- Prevent3

**orchestration**
- Prevent3

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**Header**
- Required
- Recommended
- Optional

**HL7® FHIR®**

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**CEN/EN 17269**
- International

**HL7®**
- IHE
- cdisc
- ISO
1. Collaborate across standardization bodies
   Cross-SDO alignment and cooperation

   - IHE
   - CEN
   - CDISC
   - SNOMED
   - HL7 FHIR
   - Orphanet
   - EHDSI

   **eHN EU PS Guidelines**
   - Refine
   - Provide guidance for EU
   - Implement

   **CEN/EN 17269 IPS**
   - CEN
   - CEN/TS 17288 IPS
   - Refer

   **HL7 IPS FHIR IG**

   **HL7 IPS CDA IG**
1. Collaborate across standardization bodies

Coordination of change requests to IPS value sets

- HL7 Terminology Authority
- Sylvia Thun
- Rob Hausam
- Giorgio Cangioli

Requirements
- HL7 IPS value set
- Free SNOMED CT set

EU Coordination Team
- Sylvia Thun
- Giorgio Cangioli
- Pim Volkert
- Christof Gessner

SNOMED member EU country
- National Release Centre, NCP

Non-SNOMED member EU country
- Terminology Centre, NCP

EU Member States eHealth Support (eHACTION, eHDSI)

eHealth Digital Service Infrastructure
- Master Valueset Catalogue
2. Contribute to Governance of IPS specifications Towards an «IPS ecosystem»
2. Contribute to Governance of IPS specifications

Elements of a governance framework for IPS

- **Initiative** -
  - aim of the patient summary initiative and stakeholders involved in exchange

- **Specification and Standards** –
  - patient summary specification developed or used in the initiative, the extent that standards are referenced in the specification or exchange infrastructure

- **Governance Scope and Objectives** –
  - governance in place for the initiative, responsible parties, embedding patient governance, current & future scope including sustainability

- **Stakeholder Involvement** –
  - stakeholders involved in patient summary exchange, responsible parties for patient summary governance, parties with particular purpose or indirect role

- **Update and Version Management** –
  - for any specification to remain relevant in health care and health informatics, specification updates and version management need full alignment with the maintenance of the underlying standards.
3. Bridge **grassroot patient summary initiatives**

- Signed Memorandum of understanding with 5 projects and initiatives:
  - ESH initiative on mobile health
  - C3Cloud process NICE guidelines to develop care plans for chronic disease patient with multimobility (consume IPS)
  - EUMFH hospital information system for disaster management (consume IPS of victims – produce discharge summary)
  - FrailSafe frailty assessment of elderly (consume IPS)
  - MOCHA patient summaries for children – focus on vaccination (home based records – yellow card of WHO, European vaccination card)

- Provided tools and data sets to support these initiatives in aligning with the IPS

Possible Next steps: Similar activities to support EEHRxF
4. Highlight the social value of patient summaries and health data

- **UN agencies and WHO**: executive director report on mobile health to the WHO assembly, 2018
  
  - The concept of making international patient summary data available through mobile technologies will increase the safety and quality of care by providing secure access to the information needed by the attending physicians at the time of care. This is particularly important in the event of disasters, emergencies and other unplanned care. Mobile technologies allow individuals to have access to their own summary health records and give physicians timely access to these records, which is particularly important when patients seek care outside of their normal care settings."

- **Trillium II mentioned in WEF report on value based care**
  
  - Laying down the foundation for health system transformation
  - Connecting patient summaries to outcomes, quality and safety
  
  - **Possible Next steps**: Advance link of patient summaries with clinical and patient reported outcomes.
5. Develop, Collect, Assess learning resources on patient summaries

Trillium II found limited education material on patient summaries

• What Trillium II did:
  • Created IPS standards presentation with voice over in English
  • IPS material in 6 languages: Danish, Italian, English, French, Spanish, Catalan
  • Offered webinars, presentations, 17 workshops organized around the globe
  • Developed and educational strategy with learning objectives addressing health professionals and patients
  • Developed an evaluation framework to help monitor progress
  • EFMI would have a role to play in taking these actions forward

Possible next steps: Support education on cross-border IPS services?

• Develop educational material in your language
• Build capacity among all stakeholders, including other stakeholders, e.g. Policy makers, politicians
6. Foster innovation & inform health policy

- Framed IPS standards as infrastructure for innovation
- Business canvas to work on IPS business model
- Active participation datathon, hackathon, connectathon
- Engagement in disaster medicine EUMODEX exercises
  - EUMODEX RO Bucharest, 2800 participants, 28 countries, broad spectrum
  - EUMODEX EE Saaremaa, 350 participants, Medical

What’s next: Explore the notion of modelling, visualizing and Interacting with synthetic IPS patient summary and population health data
7. Engage mobile Health companies & app developers
Competitions and Prizes!!!

Prizes for innovative use of IPS standards and tools

**MIE2018 Datathon 1st Prize:** Pharmacy app combined IPS connected to the WHO Upsala monitoring center via webservice to identify potential adverse events.

**Hacking Health Athens, Feb 2019:** use IPS to support paramedics and reroute in suspected stroke, mother-child health record

- **Trillium II Prize:** shared in fine examples of *incremental innovation* extending the shared medication service of Denmark cross border (trifork) *disruptive innovation:* IPS with medication and nutrition in capable project (U of Oslo).

**For the next steps:** IPS start-up toolkit to accelerate implementation for mobile world

Can you facilitate creation of High value IPS data sets to share and exchange?
8. Establish a **Global IPS Community of Practice** for Digital Health Innovation to build capacity

- What is the IPS Global Community of Practice?
- For the IPS Community of practice
  - **Domain of knowledge**: knowledge of IPS standard and tools
  - **Community**: mutual learning fostering interactions and sharing of experience, mentorship
  - **Practice**: IPS implementation, agile, events, testing, hackathons, datathons, ideas and data sets, feedback from implementation.
- In the end the IPS community of practice is our reference site for our shared knowledge, the meeting place of the IPS community.

**Next steps:**
What will sustain the IPS Community of practice across the Atlantic? More bridges to build so as to turn the strategic intent into capacity to act!
Global IPS Community of Practice

Co-creation
Governance
Alignment

Citizen  Workforce
Health System  Market

Time for Trillium III?

Questions?
Extra slides
Trillium-II coordination and support action in EU and USA
4 SDOs, 10+health systems and competence centers, R&D, networks, ecosystems

Standards Organizations:
- HL7 International Foundation (Scientific Coordinator), BE
- NEN/CEN TC 251 Health Informatics, NL
- IHE EUROPE, BE
- CDISC EUROPE FOUNDATION, BE

Health Systems & Associated Competence centers:
- MedCom (Administrative Coordinator), DK
- LISPA - LOMBARDIA INFORMATICA, I
- THL - TERVEYDEN JA HYVINVOINNIN LAITOS, FI
- eSANTE - AGENCE eSANTE, LU
- TicSalut – Catalunia, ES
- SPMS, PT
- Reliant, Reliant Medical Group, Inc., US
- HSCP Healthcare Services Platform Consortium, US
- KAISER FOUNDATION HOSPITALS, US

Dissemination and Networking:
- ECHA - Connected Health Alliance CIC, UK
- ADI - Advanced Digital Innovation LTD UK
- I~HD - European Institute for Innovation through HealthData, BE

Development and Evaluation:
- GNOMON Informatics SA, Greece
- PHAST RESEAU Association, France
- SRDC, Turkey
- OFFIS EV, Germany
- EMPIRICA, Germany
- LANTANA Consulting Group, LLC, US
- PROSOCIAL Applications INC, US

Other Parties
- The Sequoia Project and eHealth Exchange, US
- AHIMA, US
Mission EU/US Memorandum of Understanding

“To support an innovative collaborative community of public- and private-sector entities working toward developing, deploying, and using eHealth science & technology:

• to empower individuals
• to support care
• to advance clinical outcomes
• to enhance patient safety, and
• to improve the health of populations.”

Critical Levers:

• International interoperability
• workforce development
• innovation ecosystem
3. Bridge **grassroot patient summary initiatives**

HL7 FHIR IPS, HL7 CDA IPS, CEN IPS, IHE IPS

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**The International Patient Summary**

- **Medications**
- **Allergies / Intolerances**
- **Problems**
- **Immunizations**
- **Results**
- **Procedures**

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**EEHRxF**

1. The IPS document
2. The IPS data blocks

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**Current Intended Use**

as a **document**

as a **document** and as a **toolset for digital health systems**
2. Contribute to Governance of IPS specifications eStandards Roadmap: co-creation governance alignment

- **Trust and Flow**: the basis of well-functioning digital health systems
- **eStandards digital health Compass**: Respect for perspectives of stakeholders
- **eStandards Roadmap Components**: reusing eHealth artefacts
- **Co-Creation, Governance, Alignment**: bringing them all together
8. Establish a **Global IPS Community of Practice**

Use of IPS through a personal lens

- **Listening to the patient and the family**
  - Quality assurance: medication reconciliation by the family
  - Health goals: tracking progress and identifying health trends
  - Early warnings: frailty in the elderly

- **Navigating digital health data: portability, trust, and flow**
  - Tracking hypertension: Chronic disease management
  - Rare Disease Passport: patient summaries for patients with rare diseases
  - European Vaccination Card: Vaccination of children in communities and refugee camps
  - Survivor passport: Survivors of childhood cancer
  - Mother / Child Summary: fertility, pregnancy, child birth, infant home records

- **Tracking the health needs in communities**
  - Disaster and emergency management
  - My Healthy neighborhood

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16th eHealth Network
8. Establish a **Global IPS Community of Practice**

**Cocreation in practice**

- **Disaster Management**
- **Vaccinations**
- **Survival Passport**
- **Child Health**
- **Frailty**
- **R D-Passport**
- **Chronicity**

**FAIR research study**

**Building FHIR IPS “library”**

- Extending the scope of patient summaries beyond emergency/unplanned
- Refine the IPS components, with the knowledge gained from the project.

**16th eHealth Network**
8. Establish a **Global IPS Community of Practice** proposed followup activities

- Set up a **steering committee** and terms of reference to evaluate alternatives for a secretariat that would balance interests and would support minimum viability of the IPS Global CoP – avoid heavy weight governance, go agile

- Evaluate the **mobile HealthHub** as an alternative secretariat as it enters the sustainability phase

- Connect to the ECHAlliance international network of ecosystems

- Connect to the **Digital Health Society stakeholder movement**, which has activated a specific task force dedicated to mutual learning and good practice exchange and scaleup in the field of interoperability and standardization

- Partner the network of **Hacking Health events** – worldwide as partner to the adoption of IPS standards

- Strengthen the communities around promising partnerships with HIMSS, EUSEM, EUModex (future disaster exercises), the EFMI (e.g. collaborating in the EU-China and EU-US Health Summits events)

- Connect **local and regional communities** of practice associated with local, regional or national programs and initiatives in the frame of European recommendations e.g. EHRxF

- Work on developing/refining a suite of functionalities/offering for interoperability assets:
  - Startup kit for adoption of the IPS standards: data, servers, guidance
  - IPS Educational resources and webinars – professional certification
  - IPS Courses for capacity building - Testing, validation, and certification
  - List of events and meetups
8. Establish a **Global IPS Community of Practice**

**Trillium II – in numbers**

- Countries and continents participating in Trillium Prize awards: 1 multicountry consortium, 7 countries
- Countries with IPS workshop: China, Canada, USA, Greece, Portugal, Mercosur, etc. 17 workshops
- IPS educational material 5 languages
- Tools to accelerate standardization: Develop IPS (CEN, HL7, to ISO) <2 years
- Tools to accelerate standards implementation for interoperability < 2 days
- IPS out of the doctors/emergency office 5 domains
- Testing: Hack- Dat- Connect-athons (3 events) > 800 participants
- Disaster exercises – evaluation 2 exercises (4000pp)
- Community of Practice Outreach >5500 persons
- Newsletters, ECHAlliance, HL7, IHE >25,000
- Total number of event attendees, subscribers, followers >38,000