Sharing information on Healthcare across Europe – Lessons from EXPAND

II European Reference Networks Conference

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Henrique Martins, Zoi Kolitsi

Lisbon, 8th October 2015
II European Reference Networks Conference

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AIMS FOR HEALTH CARE DELIVERY SYSTEM

- Equitable
- Safe
- Effective
- Patient-Centered
- Timely
- Efficient

*IOM: Crossing the Quality Chasm*, 2001
POLICY CONTEXT

• Directive 2011/24/EU on the application of Patients’ rights in cross-border healthcare promotes MS co-operation in health care on
  – recognition of prescriptions (Art 11)
  – ERNs (Art 12)
  – Rare diseases (Art 13)
  – eHealth Network (Art 14) and
  – HTA (Art 15)
EHEALTH NETWORK – PRIORITIES FOR CROSS BORDER EHEALTH SUPPORTED THROUGH CEF

- Cross-border patient summary service
- Cross-border ePrescription and eDispensation service
- eHealth services for European Reference Networks
- Infrastructure services for European patient registries
AIM OF EXPAND...

- ways forward in terms of supporting Member States to prepare for large-scale deployment of eHealth cross-border services

- EXPAND overview of its main mission:
  - how to go from pilot punctual solutions to a broad deployment of eHealth services building a bridge to the CEF making available consolidated and sustainable assets from different EC projects.
## LANDSCAPE

### eHealth Policy & Governance

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<td>eHealth Network Art. 14, Directive 2011/24/EU on cross-border healthcare</td>
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<td>eHN Support – Joint Action (beyond eH3I)</td>
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<td>Sub-Group eHealth in CEF (Connecting Europe Facility)</td>
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### Cross border eHealth-Sustainable Development Framework

<table>
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<th>Guidelines</th>
<th>Guidelines on Minimum/Non-exhaustive Patient Summary Dataset for Electronic Exchange (Adopted by the eHN)</th>
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<td>Support from running projects and upcoming H2020 PHC-34 (i+iv)CSAs on eHealth Interoperability</td>
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<th>Assets, Standards, Specifications, Profiles</th>
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<td>Business modelling</td>
<td>VALUeHEALTH (PHC-34 iv)</td>
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### National Level Activities: Generic Services Support

| eHealth National Contact Points (NCPs) |

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Expanding Health Data Interoperability Services - www.expandproject.eu 08-10-2015
• The need for EXPAND...
  – Building the bridge...

ICT PSP Objective: 3.3.c: *Sustainability of EU wide info-structure and collaborative governance*

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**eHealth assets from different projects**

... 2013  2014

**CEF**

(available for “mature” domains; with specs which may be used in procurement)

... 2015  2016 ...
• The need for EXPAND
  – Someone to cross it...

support Member States in delivering their local eHealth plans and providing cross-border care.
Coordination of upto 28 MS proposals coherence? Semantics joint efforts...?
epSOS use cases
- Patient Summary
- ePrescription/eDispensation
- PAC – Patient access to Patient Summary
- HCER – Healthcare Encounter Report
- MRO – Medication Related Overview

Parent and other EU projects

eHealth CEF use cases
- Cross-border Patient Summary service
- Cross-border ePrescription/eDispensation service
- eHealth services for European Reference Networks
- Infrastructure services for European patient registries
Description of eHealth DSI (Digital Service Infrastructures) 
(Funding Source: Member States and CEF _ Connection European Facility/Fund)

**Core services:**
- **Horizontal BB:** eID, eDelivery, elvouching...
- **eHealth BB:** terminology server
  - 100% calls for tender

**Generic services** to be supported by CEF, 75% calls for proposal

**BB:** building blocks
THE EXPAND WORKING APPROACH TO ASSETS

1st workshop
May 2014, Athens

Identify possible candidate assets beyond the epSOS

2nd workshop

Establish links with identified projects

3rd workshop
January 2015, Brussels

Validation (first instance)

Functional characteristics of EU eHealth Infrastructure

Assessment framework for candidate assets

EXPAND will provide the move from the working example of - primarily but not exclusively - epSOS to a proof of concept of generally usable and applicable assets of projects in the shape of an interoperability assets information repository.

Adoption & Handing Over

Testing & Validation

Application in EXPAND MSh

MS&CC workshop
April 2015, Lux

Consolidation
Sharing information on Healthcare across Europe – Lessons from EXPAND

VISION

- Trillium Bridge
- other pilots
- Support, preparation, and hand over to CEF
- Expanding beyond epSOS
- Registries & ERNS
- Assessment Model
- PS and ePr business use case
- Hand over of open NCP and central services
- List of interoperability assets
- epSOS assets maintenance shops

H2020 PHC-34: eStandards – openMedicine
ASSESS-CT - VALUeHEALTH
Sharing information on Healthcare across Europe – Lessons from EXPAND

Support preparation and hand over to CEF

- Expanding beyond epSOS
- Registries & ERNS
- Assessment Model
- PS and ePr business use case
- Hand over of open NCP and central services
- List of interoperability assets
- epSOS assets Maintenance shops

Other pilots

CEF SG

eHealth Network

EUCERD Joint Action

EURORDIS Rare Diseases Europe
EXPANDING...

• Liaison with eHealth Network Sub groups and Joint Actions
• EXPAND, e-SENS and STORK, effort orchestration model
  – Achieve a collaboration model that distribute effort and enhance the focus of each project:
    • EXPAND: working as governance body and technology proxy for epSOS and other eHealth mature projects assets;
    • Stork 2.0: as eID Building Block;
    • e-SENS: as Piloting project for integrating technologies:
      "Patient Summary/ePrescription" + eID use case

• New comers on board
  – 20 Members (14 countries) → 24 Members (17 countries)
    • partners willing to deploy cross-border services
PRODUCING ADDED VALUE

• Usability
• Maintenance
• Assets remit
  – Eg. MVC 2.0

• EXPAND keywords
  – Survivability
  – Expandability
  – Reusability
  – “Qualifiability”
  – “Engageability”
  – “Assessability”
  – …
ROLE OF MEMBER STATES

• Commitment to central activities
• Local Implementation
  – Organisational
    • Implementation of the Organisational Framework
    • Establishment of a National Contact Point for eHealth (NCPeH)
  – Semantic
    • Implementation and maintenance of the MTC (Master Translational Catalog)
  – Technical
    • Integration of NCP to National eHealth Infrastructure
    • Implementing and operating user interfaces for the end users Dissemination and Training
    • Providing necessary support and training for end users
EXPAND HANDOVER TO CEF

Several initiatives: TLA; Technical Orchestration; Semantic revision; Bilateral opportunities exploration (PT-LUX; FIN-SWEDEN; PT-UK, PT-SP)
SHOPS ORCHESTRATION

- Legal & Organizational
- Specifications
- Semantic
- Technical
- Testing
- Deployment
- Operations
- EC Guidelines
- Legal/Security Assets
- OpenNCP: SW+Specs
- Clinical document Implementation Guides
- Terminology (MVC / MTC) + procedures
- Deployment/Operation/Management Guidelines
- Central Services
### SHOPS ORCHESTRATION

#### Legal & Organizational Specifications

- **Semantic Testing**
- **Deployment**
- **e-SENS**
  - Define infrastructure based on Building Blocks from LSP
  - **eHealth Domain**: Improve existing epSOS Infrastructure integrating e-SENS Building Blocks to **solve issues**

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<th>Relevance</th>
<th>PROBLEM</th>
<th>BB</th>
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SHOPS ORCHESTRATION

Legal & Organizational Specifications
Semantic Specifications
Testing
Deployment Operations

Assumptions & Constraints

Engineering framework to delimit 5.2 boundaries:

- ECCF
- Enterprise Dimension "Why" Policy
- Information Dimension "What" Content
- Computational Dimension "How" Behavior
- Engineering Dimension "Where" Implementation
- Technical Dimension "Where" Deployment

e-SENS – EXPAND – OpenNCP: Joint implementation
Find solution to cross-charge
SHOPS ORCHESTRATION

**Legal & Organizational Specifications**

**Trillium:** Build the **Bridge** between EU / US, in line with MoU

- 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
SHOPS ORCHESTRATION

- Legal & Organizational Specifications
- Semantic Technical Testing
- Deployment Operations

OpenMedicine
- Joint assessment on adoptability of EMA Article 57 Database for Pharmacovigilance, to improve the quality of Cross-border eP/eD

New Ongoing
ASSET ID ... CONNECTED PEOPLE...
eHealth Strategies and Roadmaps supporting European Reference Networks and rare disease policies

Zoi Kolitsi, AUTH

work carried out in cooperation with the EUCERD Joint Action for RD, the PARENT Joint Action for Registries, and EURORDIS
ISSUE AT STAKE

• Rare disease and e-Health policies and strategies addressed separately and largely without coordination to-date
• Interoperability remains an important challenge for sharing data for care and for research
• Need to create convergence between the eHealth and the public health communities
BEYOND CROSS BORDER PATIENT SUMMARY AND EPRESCRIPTION SERVICES

• **Improve emergency care for RD patients, for example…**

  “**RD specificities in the European Patient Summary** may be envisaged as an extension of the current data set to include data elements necessary for identifying RD patients and for adequately conveying core information on rare conditions and treatments.”

• **From emergency care to planned care, supporting ERNs, for example…**

  “**Supporting planned care through shared care records** may be envisaged as an evolution of the Patient Summary service to address the needs of planned care, starting from selected diseases.”

• **Linking health care to research, for example…**

  “**Extending eID services** provided for Patient Summary and ePrescription needs, to include the Global Unique Identifier for patients/research participants** which could allow clinicians and researchers to ‘link’ genome sequencing data with essential phenotypic information gathered in shared care EHRs.”
BUILDING ON EHEALTH DIGITAL SERVICE INFRASTRUCTURE...

It is sensible to assume that extensions of cross border eHealth DSIs will need to demonstrate that:

- there is a clear *policy priority under Directive 2011/24/EU*;
- there exists an infrastructural need at a European level that addresses an *important integration gap* and will *deliver real added value* to the implementation of this policy if it is met;
- this integration functionality will *not* be provided through the services that the CEF already plans to deliver, and
- the additional interoperability services can draw on *mature specifications and standards* that have consensus acceptance within the user community.
OPEN ISSUES

• Current projects and Joint Actions
  – Will continue to support a certain level of co-operation e.g. joint workshops,
  – Will validate and publish an Exploratory paper

• New (homeless) needs
  – Identify appropriate candidate use cases for a possible extension of eHealth in the CEF 2016 programme,
  – if eHealth extensions will be included in the CEF 2016 work programme, **a supplementary activity** to prepare assets for these extended CEF services **will become urgent**,
  – reflect on and deliver **a proposal for a Roadmap of use cases and associated work elements** necessary to address in a stepwise and prioritized approach the full span of cross border eHealth needs implicit in the Directive
  • a valuable policy support instrument in terms of setting common EU implementation priorities.
Lisbon eHealth week
Dec, 9 to 11th 2015

L (TLA, Legal Framew.)
O (NCP)
S (MVC 2.0)
T (EXPANDathon)

&

FUND

Fun
Understand
Navigate
Do it...
EXPAND FINAL EVENT – Lisbon eHealth week

• Aims:
  – To convey the results of EXPAND, contributing to critical mass among the different Stakeholders in preparation for deployment of cross-border eHealth services.
  – To collect testimonials about how the results of the EXPAND have been contributing to the readiness of Stakeholders concerning cross-border eHealth services deployment.
  – To give Member States the opportunity to assess their readiness for deployment of cross-border eHealth services.
  – To disseminate and engage with a wider group of stakeholders, including patients and health professionals.

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EXPAND FINAL EVENT - Lisbon eHealth week

• Audience
  – Member States, Competence Centres, EU Projects, European Commission, Patients/Citizens, Health Professionals, ICT Industry

• Objectives
  – 9th Dec - Wednesday
    • High level stakeholders/policy makers engagement, presenting the EXPAND results and highlighting its contributions to the maintenance and handover of assets to CEF.
  – 10th Dec. - Thursday
    • Practical support to Member States to best exploit EXPAND assets and guidelines towards their own preparation for CEF call.
  – 11th Dec. - Friday
    • To discuss how EXPAND results may impact cross border eHealth services for patients and health professionals.
  – 9th to 11th - EXPANDathon
    • To give Member States the opportunity to collect evidence on their readiness for deployment of cross-border eHealth services.
Thank you for your attention!

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