The approach to developing and promoting interoperability assets for continuity and shared care – the heart failure example

Veli Stroetmann, MD, PhD

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Health system interoperability

The ability, facilitated by ICT applications and systems,

- to exchange, understand and act on citizens/patients and other health-related information and knowledge
- among linguistically and culturally disparate health professionals, patients and other actors and organisations
- within and across health system jurisdictions in a collaborative manner
SemanticHEALTH recommendations 2006-2008

• A strong and *coordinated effort* needed to effectively engage with all relevant stakeholders:

  policy makers and health authorities, national competence centres, service providers, health professionals and professional organisations, citizens, academic organisations & research funding agencies, SDOs, industry, insurance sector

• Establish sustainable national bodies

  e.g., national centres for multilingual, multicultural adaptation of international classifications and terminologies), linked in resp. European networks

  **There is a need for**

  **sustainable structures that are inclusive + governed processes + widely available tools**
SemanticHealthNet concept and objectives

- Leverage a **clinically-driven work-plan**
  - heart failure, exemplifying chronic disease management, evidence based care and shared care: focus on individuals who are patients
  - cardiovascular prevention, exemplifying public health and national / global strategies: focus on populations who are citizens
- Bring together the **globally best of breed** semantic resource producers including commitment from the top SDOs
- Draw on a **rich body of expertise** including past EU projects in the EHR, semantics, semantic interoperability, wide-scale record sharing and eHealth governance + the new projects
- Maximise stakeholder engagement and resourced commitment to ensure we focus on **usable and useful and affordable solutions**
- Robust **business approach**: people, processes, products, platforms
- Develop a **scalable, sustainable, well-governed** European Virtual Organisation for semantic interoperability
SemanticHealthNet approach to sustainability 2011-2015

**Workstream I**
- **WP 1**: Patient care exemplar: chronic heart failure
- **WP 2**: Public health exemplar: cardio-vascular prevention

**Activity domain: Tangible evidence (RTD)**

**Workstream II**
- **WP 3**: Stakeholder validation
- **WP 4**: Additional conditions and patient populations
- **WP 5**: Professional communities
- **WP 6**: Clinical governance
- **WP 7**: Citizen communities
- **WP 8**: Health authorities
- **WP 9**: Global public health

**Activity domain: Generalisability & scalability and sustainability (OTH)**

**Workstream III**

**Sustainability Network co-ordination**
- **WP 7**: Adoption & sustainability strategies
- **WP 8**: Business success factors
- **WP 9**: Sustainability models

**Workstream IV**
- **WP 10**: Harmonised resources for EHRs/PHRs & aggregation
- **WP 11**: Aggregation

**Workstream V**
- **WP 12**: Industrial engagement
- **WP 13**: Integration into clinical/public health information systems
- **WP 14**: Industrial exploitation
- **WP 15**: Recommendations to SDOs

**Workstream VI**
- **WP 16**: Harmonised information architecture & tools
- **WP 17**: Artefact governance, certification & testing

**Workstream VII**
- **WP 18**: Information infrastructure & tools
- **WP 19**: Artefact governance, certification & testing

**Workstream VIII**
- **WP 20**: European Virtual Organisation
- **WP 21**: Community building
- **WP 22**: Organisational governance
- **WP 23**: Liaison with EU initiatives
- **WP 24**: Liaison with national bodies
- **WP 25**: Education, training

**Workstream IX**
- **WP 26**: Project management, dissemination, promotion (MGT)
SemanticHealth levels of semantic interoperability

- **Level 0**: no interoperability at all
- **Level 1**: technical and syntactical interoperability (no semantic interoperability)
- **Level 2**: two orthogonal levels of partial semantic interoperability
  - **Level 2a**: unidirectional semantic interoperability
  - **Level 2b**: bidirectional semantic interoperability of meaningful fragments
- **Level 3**: full semantic interoperability, sharable context, seamless co-operability

Source: Veli Stroetmann et al, SemanticHEALTH
What were we trying to do, and why Heart Failure (HF)?

• Develop a useful and credible electronic health record for use in patients for HF, as an exemplar of other chronic conditions
• **Starting with a shared Care Summary**
  – This must contain basis for a reliable diagnosis
• Complex diagnostic, treatment and management issues
• Potential for effective self management
• 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
• 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
Heart Failure example – interoperability needs

- Communication needs and data flows

- HC plus reuse of data for research, population management, public health, etc., also across borders (institutional, national, ..)
- Many actors involved in various threads of communication, different ICT systems - complex interoperability needs
The HF Information Landscape

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

Source: John Cleland, Suzanna Hardman, SHN 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 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
Collation of Heart Failure Data-Sets & Guidelines
Specification of Scenarios

- **Existing trial data-bases delivered**
  - Hull Life Lab Data-Base
  - SICA-HF (FP7 funded epidemiology study of HF)
  - UK National Audit Data-Base

- **Heart Failure Guidelines Collated**
  - European Society of Cardiology
  - American Heart Association/American College of Cardiology
  - Heart Failure Society of America
  - NICE Guidelines and Quality Standards
  - SIGN
  - Australia & New Zealand Guidelines

- **Heart failure summary use case and exemplar scenario**
  - Clinical setting in which semantic interoperability leads to improved coordination of care and avoided complications
  - EHR/summary data re-use for research purposes, clinical audit and population health management

Source: John Cleland, Suzanna Hardman, SHN WP1
Heart failure summary use case and exemplar scenario

CLINICAL SCENARIO:

- Diabetic patient with heart failure (HF) & chronic kidney disease (CKD) admitted on Friday evening to the emergency department of the general hospital for tender peripheral oedema and worsening shortness of breath
  - A&E department refers patient to Medical Admissions Unit (MAU) for stabilisation
  - A renal consultant changes the patient’s HF medications as he thinks they’re interfering with the renal function
  - Admission and medication changes are picked up by the EHR system used by the HF specialist (informed by the cardiology clinic about the change, through an ad-hoc alert)
  - Specialist issues an alert advising against the therapeutic change and offers alternatives
  - Patient’s GP receives prescription history with reasons for the change and a new decisional pathway to monitor the renal function
  - Specialist nurse is informed of the plan and schedules a visit

SEMANTIC COMPONENTS:

- Mapping between different EHR systems, enabling different views, summary notifications, identifying potential adverse drug events

ADVANTAGES AND IMPACTS: Reduced risk of:

- lengthy admission to resolve further decompensation due to lack of coordination
- adverse drug reactions
- Repeated medications errors on discharge

POSSIBLE MISALIGNMENTS of incentives

- Cardiology hospital does not receive a referral / less patients
- Specialist electronic consultation time may not be reimbursed (sufficiently)
Cost-benefit analysis - evidence from literature

Issues with existing studies

• Overstated estimated benefits assuming best case scenarios
  – Only take saved financial transactions into account but not improvements in quality of care or clinical workflow
  – The only reliably documented benefits were those regarding
    • Efficiency, including improved access to test results and other data from outside the practice and
    • Decreased staff time for handling referrals and claims processing

• Ignoring developing cost of standards and connectivity cost between stakeholders

• No account for lost revenues e.g. from changes in utilisation (e.g. avoided tests)

• Neglect economic incentives of healthcare providers
HF summary scenario: key cost factors

- Investment costs for creating a heart failure summary as an extension of the patient summary
- Technical representation in different EHRs
- Access to reusable assets such as semantic metadata registry, data formalisation tools, data transformation tools, mappings among code systems, a supporting terminology server, could reduce efforts to a great extent
- Regional interchange platforms including semantic broker
- Price reduction following achieving a critical mass
- Change management cost
- Legacy system replacement
- Maintenance costs (certification and re-certification, terminology updates & mappings)
HF summary scenario: key potential benefits

- Better treatment outcomes
- Avoided adverse drug events
- Effective care coordination (e.g., informed remote consultation instead of specialist visit)
- Effective procedures (efficiency savings)
- Predicted / avoided admissions (improved predictive analytics)
The framing conditions for realising the SHN SIOp scenarios

- Epidemiology of heart failure
- Spending on heart failure
  - Difference in general spending is based on the numbers of chronically ill patients and the standards of care
The framing conditions for realising the SHN SIOp scenarios

• The eHealth market characteristics
  – Constant change due to technological advances
  – Changing vendors competitive advantage

• Existing technology and infrastructure

• Recognised and adopted SIOp standards can reduce software development costs

• eHealth overall strategies (national, regional, local)
  – Strategies are important for development and expectation of benefits

• Shortage of eHealth, health informatics and health analytics skills
Stakeholder involvement

• Health professionals: SIOp will change the workload of healthcare professionals (Time savings, additional tasks, tasks shifted to other professionals)

• Third party payers
  – Beverage payers influence how care is commissioned
  – Bismarck payers have no immediate influence on commissioning

• Population health
  – Health outcomes of a group of individuals (including the distribution of such outcomes)
  – Aims to improve the health of an entire population
  – Lack of adoption of interoperability can be attributed to the lack of an organisation moderating and facilitating between all different stakeholders

• Multi-stakeholder value chain ensures the creation, delivery and capture of value

• Combination of top-down and bottom-up approaches will ensure optimization of value across stakeholder groups
Realising benefits from semantic interoperability: what is cause, what effect in a complex system

**Measures**
- Technical standards and certification
- Semantic standards and terminology
- Data protection and regulation
- Identification and authorisation
- Subsidies and funding
- Administration

**Outputs**
- Technical interoperability
  - ICT products rely on same standards
  - Security of investment
- Semantic interoperability
  - Making sure data can be used by others for other purposes
- Legal, regulation and security
  - Content: which data to link?
  - Access: Who is allowed?
  - Liability & security
- Minimising misuse
  - Secure electronic identification of patients and clinicians
  - Regulation compliance
  - Cyber-security measures
- Additional incentives for use
  - Training
  - Shared financial models
  - Knowledge transfer
- Administration of access right
  - Compliance reviews

**Outcomes**
- Investment in ICT Systems
- Connecting stakeholders: hospitals, researchers, GP practices
- Exchange of clinical data along the clinical workflow
- Population health
- Research
- Organisational change
- Active use

**Impacts**
- Costs
  - Investments
  - Running costs
  - Admin. costs
  - Restricting area of operation
- Benefits
  - Quality of treatment
  - Access to treatment
  - Efficiency
  - Improved research
  - Sensitivity, optimism bias and risk
  - Adjusted costs
  - Adjusted benefits
  - Adjusted net benefits
A multi-standard neutral organisation is needed to establish and promote the value of semantic interoperability

- Continue shaping the business case of semantic interoperability by collecting and synthesising existing evidence framework
- Develop strategies with government to secure sustainability of interoperability
- Reduce investment risks by developing risk mitigation strategies and communicating those to stakeholders
- Consolidate the experience from interoperability initiatives e.g. upscale process already tested by HF focus SHN

➢ One key activity is building up an evidence base

To collate and synthesise worldwide experience and learning of success strategies for scaling up SIOp, of demonstrating value and deriving benefits from SIOp
Networking all stakeholders - the initial ideas

European Virtual Organisation for Semantic Interoperability and Infrastructure: Potential Members & Users/Supporters

Potential Core / Founding Members:

SHN coordinator EuroRec
WHO, IHTSDO
SDOs (HL7, EN13606, ...)
National Centres
(e.g., ASIP Santé, DIMDI, ...)
...

Key aspects to be analysed by SemanticHealthNet:
1) Organisational structure & governance mechanism
   (e.g., Board, Secretariat, Core members, Members, Advisory Boards, other Stakeholder Groups)
2) Mission, objectives, terms of reference; core activities & services, processes, liaison
3) Budget, long-term sustainability strategy

Global Outreach / Dissemination / Liaisons
(e.g., epSOS, ARGOS, OHT, JIC, ...)
Sustainable Semantic Interoperability – key stakeholders

1. Patients, Patient Associations
2. Health Professional Associations, Clinical Specialty Associations
3. Healthcare Professionals
   - Clinicians, nurses, pharmacists
4. Healthcare Provider Organisations
   - Hospitals, GP practices, etc.
   - Healthcare managers & administrators
5. National Decision Makers
   - Health ministries
   - Public health bodies
   - National & regional healthcare authorities
6. Payers
   - Private (insurers, employers, patients)
   - Public (government, commissioners)
7. Industry
   - EHR System Vendors
   - Medical Device Vendors
   - ICT Infrastructure Vendors
   - Industry Associations
   - Pharma
8. Standards Development Organisations
9. Research
   - Healthcare R&D
   - Health informatics R&D
10. Multi-National Decision Makers
    - WHO
    - EC
    - OECD...
11. Social Care Providers
13. eHealth Competence Centres/Competence Authorities
    - gematik, ...
14. Media

Source: SSI-TF 2013
An Evolving Business Model
Optimizing Value from Limited Top-Down to Value Chain Approach

Tier I
- Decision/Policy Makers
- Public/private payers

Tier II
- Health ICT Industry
- SDOs
- Health ICT Research

Tier III
- Professional Associations
- HCP/HPO
- Clinical Research (public/private)

Tier IV
- Patients
- Citizens
- Carers

Funders of SIOP Solutions
Providers of SIOP Solutions
Users of SIOP Solutions
Beneficiaries of SIOP Solutions

Delivering Value
Creating Value
Capturing Value

Limited Resources
Gvt/Public Funding
SDO/Industry
HPO/HCP/Public Health Research
Patients

Patients
HPO/HCP/Public/Private Research
SDO/Industry
Public–Private Partnerships

Deliver Value
Beneficiaries
Users
Providers
Funders

HealthNet
Sustainable support to European interoperability efforts

• **European Institute for Innovation through Health Data**
  - A new European not for profit body, registered in Belgium
  - Mission: To enable, coordinate, and accelerate the efficient development and deployment of interoperable and seamless eHealth solutions and research strategies, towards achieving best practices and sustainable integrated person-centred health care, to optimize health and wellness in Europe, and beyond

• **Two Centres of Excellence (CoE):**
  - CoE for Semantic Interoperability
  - CoE for the Research Use of Health Data

Founding projects:

Contributing projects: 
Semantic Interoperability Centre of Excellence

• **Objectives**
  – Fostering the design and validation of SIOp assets by clinicians
  – Quality labelling and registering interoperability assets
  – Designing quality processes for clinical information models
  – Promoting interoperability standards implementation and adoption
  – Leading an Alliance of standards developers, implementers, purchasers and users
  – Providing tools to support semantic harmonisation

• **Scope of activities**
  – Quality labelled interoperability asset register and infostructure
  – Best practices in interoperability asset development
  – Semantic interoperability evidence base
  – SemanticHEALTH Alliance
  – Semantic harmonisation services
Follow up activities: VALUeHEALTH

1. We will develop a **prioritised set of use cases** reflecting Member State health business needs for cross-border and within-border digital services on a European scale.

2. Through state of the art methodologies, VALUeHEALTH will design an over-arching **business model framework** that encompasses and delivers customised value propositions across a wide range of relevant stakeholders, a Cost Benefit Assessment, risk assessments and sustainability strategies.

3. We will develop a **roadmap of scale-up adoption strategies**, critical success conditions, recommended incentives and who should fund them.

4. We will develop an **ICT and interoperability deployment roadmap**, defining the critical digital infrastructure services that are needed to deliver the priority use cases, and the interoperability assets and platform services that will be needed to design, implement, deploy and maintain these services.

5. We will deliver a **Business Plan and Sustainability Plan** which will identify sustainable streams of revenue to establish, operate and grow pan-European eHealth Services beyond 2020, when such services will need to be self-funding.
The VALUeHEALTH work plan

Multi-stakeholder engagement & endorsement

Interoperability asset collation

- Legal, contractual, procurement
- Organisational change, education and guidelines

Asset alignment, profiling, bundling

- Semantic assets: data structures and analytics
- Technical assets: structures, formats, security

Collaboration with SDOs, and industry

Adoption and incentives roadmap

Business model for sustainability

Design and deployment roadmap

Business plan for interoperability beyond the CEF

Use case inputs from epSOS, Antilope, SemanticHealthNet, EXPAND, PARENT...
and from eHealthNetwork, healthcare providers and patient associations, industry

Roadmap of prioritised use cases for interoperability
A quote from industry

“You can only break through this chicken egg problem by the believe in and the execution of a long term investment, which goes beyond one vendor can do, even one country, the solution should be a network of networks and not just one network. “

An SHN member from industry
Thank you for your attention!

Contact:

dr. empirica Gesellschaft für Kommunikations- und Technologieforschung mbH
Oxfordstr. 2 - D-53111 Bonn – Germany
Tel: +49-228-98530-42
eMail: Veli.Stroetmann(at)empirica.com

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