International Patient Summary Standards in Child Care: state of play, home-based records and business canvas

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Secretary General

HL7 Foundation, Brussels, Belgium

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“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 ecosystems

Trillium Bridge 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.”

February 26, 2019
Digital Health and Wellness Summit, MWC2019
CEN-HL7-SNOMED Agreement: International Patient Summary Project Deliverables

EHN: Patient’s rights to cross-border care

EUMODEX2018
Disaster medicine and emergency Response, Oct 14-16, Romania

Europe
Vaccination Card

HL7 IPS
FHIR IG

SNOMED IPS Free Set

HL7 IPS
CDA IG

SNOMED IPS Principles
Implementable
Applicable for global use
Extensible and open
Sustainable

CEN/EN 17269
IPS

CEN/TS 17288
IPS

provide EU IG

refine
eHN EU PS Guidelines

European
Vaccination Card

My Health, My data, where I need them

HL7 Int. & CEN/TC 251 agreement (April, 2017)

HL7 Int. & SNOMED agreement (February 2018)
International Patient Summary
Supporting the EHRxF

Current Intended Use
as a document

February 26, 2019

as a document and as a toolset for digital health systems

February 26, 2019

Digital Health and Wellness Summit, MWC2019
**Scaling-up the use of patient summaries**

*In case of Emergency, the IPS is there in our mobile phone and can be understood anywhere in the world*

*Emergency response teams can use aggregated IPS to capture the needs of a community or refugee camp in the aftermath of a disaster.*

Trillium-II’s ambition touches the person through their personal hub and the community through an aggregating dashboard making the most of our data-driven economy.
Trillium II: Scaling up international patient summary (IPS) standards

- Highlight the social value of patient summaries and health data
- Contribute to their Governance of IPS specifications
- Develop, Collect, Assess learning resources
- Foster innovation & inform health policy
- Collaborate across standardization bodies
- Bridge grassroot patient summary initiatives
- Engage mobile Health companies & app developers

Establish a Global Community of Practice for Digital Health Innovation using International Patient Summary Standards (IPS)

February 26, 2019 Digital Health and Wellness Summit, MWC2019
Patient summary as Health data navigator

Think of the Patient summary as a window to a person’s health or dashboard to support actors in a person’s health and care:

- Medications, allergies, vaccinations, problems and procedures,
- labs, diagnostic imaging, recent or planned encounters, implantable devices
- advance directives

“Bring the Power of Platforms to Health Care” using data to drive:

- administrative automation, networked knowledge, and resource orchestration [Bush & Fox, HBR November 2016]

eStandards need to

- help build trust
- unlock the power of health data
- facilitate decision support
- navigate the health system
What does this mean for YOU?  
Uses of the 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
Trillium II - Collaboration with the MOCHA project

- MOCHA aims to appraise Models of child health for primary care across 30 countries
- MOCHA and Trillium II collaborate on elaborating IPS for paediatric emergencies
- Trillium II and MOCHA to liaise on immunization info in the IPS and liaise to ECDC as related to Immunization Information Systems

- MOCHA and Trillium II organized
  - Workshop at CEN/CENELEC, Brussels September 18-19, 2018
  - Workshop at WHO Europe, Copenhagen November 21-22, 2018

- Follow-up actions of these activities
  - Feasibility of supporting the European Vaccination Card with IPS
  - Promoting Digital Health Literacy for adolescents focusing on autonomy
  - Evaluating the value of Patient Summaries in Community Pharmacies
  - Exploring the value of Patient Summaries for Children with complex with needs
  - Connecting patient summaries with Immunization Registries
  - Evaluating patient summaries for home based records
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Towards integrated pediatric care; solutions, effectiveness and safety considerations
Rianne Oostenbrink (ErasmusMC-Sophia Rotterdam, REPEM), Luis Garcia-Castrillo Riesgo (EUSEM), Michael Rigby (Imperial College London, MOCCHA), Frederik Ehler (HUG), Lembit Pirn (Health and Welfare Information Systems Center, Estonia), Catherine Chronaki (HL7 Foundation)

AIM

to study if the International Patient Summary (IPS) standard comprising a minimal and non-exhaustive specialty-agnostic, condition-independent, but clinically-relevant collection of clinical and contextual information, can be used to integrate health data for children

Methods

We described pathways identifying main components or care covering preventive, family, supportive, and acute care. Data were retrieved from large collaborative studies and guidelines.

Results

Electronic health record (EHRs) exist at focal points but lack information transfer. Resources are accessible to health policy makers or researchers mostly. Data are influenced by variability of health care structures.

Conclusions

IPS could link health data at transition points for prompt feedback. Needs rules on what data to use and how to present them across the pathway to empower patients to access and amend IPS data.
HL7 FHIR: key to value based care

- **APIs in healthcare open ways so that:**
  - Citizens access their health data on the phone through transparent agreements of handset manufacturers and providers
  - Citizens can make their own data available for further care

- **Patient data are used to develop services for patients to manage their health, make better care and informed choices.**
  - digital health advisors that can respond to consumer questions based on users’ unique health care data and informed by artificial intelligence, e.g. symptom checkers
  - Gadgets/ apple watch wrist band
  - Telemedicine – remote diagnosis – citizen science
  - Digital health literacy, education for patients with chronic disease

Digital Health and Wellness Summit, MWC2019
Business Canvas for HL7 FHIR IPS

- Key partners & Suppliers
- Key activities and Revenues
- Value Proposition
- Customer Relationships and Channels
- Customer Segments
- Cost Structure
- Revenue Streams
IMPACT OF EUROPEAN EXCHANGE FORMAT OF EHRs ON:

CITIZENS
PEDRO
Pedro, Spanish, is visiting his friend Manuel in Vienna. Unfortunately, as he walks down the street, Pedro slips and hits his head on the ground and loses consciousness.

He’s led to a nearby hospital to get an urgent life-saving operation. Since Pedro’s Electronic Health Record is accessible in Austria, all previous operations, allergies and intolerances are available. Pedro is safely operated and can join his friend Manuel for a nice cup of coffee.

MEDICAL PROFESSIONALS
ELENA
Elena is a Bulgarian doctor who examines many expat patients. When Jean consults her with a persisting very high blood pressure, she can easily access his Electronic Health Record and medical history. This saves her time to enter information in her system about his age, weight, intolerances and allergies.

She can also see how Jean reacted previously to medication when he was treated for his high blood pressure. This makes Elena’s life easier, since she can quickly diagnose Jean and prescribe him the best medication to which he would react positively.

PUBLIC ADMINISTRATORS
GIUSEPPE
Giuseppe works in an Italian hospital which is regularly referred patients from other EU Member States. Having the ability to receive and read the Electronic Health Record of his foreign patients makes it easy for him to know what relevant tests have been performed recently and avoid repeating them. It also saves the patient from unnecessary intrusive testing and lowers the costs for the hospital.
APPLY for the #TrilliumIIPrize

Deadline 1st May
Extra slides
Business Canvas for HL7 FHIR IPS: Key Partners and Suppliers

Key partners:

✓ Healthcare Providers: need to incorporate IPS in their eHealth strategy for safer patient mobility
✓ health authorities: setting certification criteria for apps boosting demand for services & standards
✓ Telecomm companies: interested in incorporating health services in their digital offer
✓ Mobile health companies developing complementary apps
✓ Healthcare Software Providers: seeking new services to incorporate in the EHR or HIS they offer/manage
✓ Venture capitals/investors: seeking for innovative breakthrough services
✓ Insurances: seeking to benefit from IPS data collection for better risk assessment and new client services
✓ Healthcare professional associations: influencing offers and guiding demand for mHealth apps embedding specific services and standards by testing and validating apps

Key suppliers:

✓ SDOs
✓ Terminology organizations

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Business Canvas for HL7 FHIR IPS: Key Activities and Resources

Key activities

✓ Integration of IPS in mHealth app
✓ Promotion and marketing actions to create awareness of the added value of having mHealth apps complying with IPS standards
✓ Participation in standardization groups
✓ Participation in datathons, connectathons, and similar.

Key Resources

✓ HL7 FHIR Foundation
✓ Trillium II digital health innovation community
✓ eHDSI Resources and Governance
✓ Agreements with terminology organizations (SNOMED)
✓ Standardization groups
✓ Resources such as datasets, servers and tools provided by the SDOs
Business Canvas for HL7 FHIR IPS: Value Proposition

Value for citizens:

✓ Ease cross border health data mobility
✓ Increase safety in travelling
✓ Ease emergency and disaster response
✓ Ease chronic disease self-management

Value for mHealth app developers: By adopting IPS they

✓ get a set of resources to enhance their service offerings
✓ become part of a co-creation environment for building and expanding the IPS components
✓ can easily integrate with or be acquired by mainstream companies
citizens are the final beneficiaries of the IPS integrated in the mHealth apps they use

**Types of customers and customer relationships:**

- Citizen as direct clients of the mHealth app developing company (B2C relationship):
  - search for apps they need in a marketplace, pay for subscription or use, review apps and contribute in iterative co-design processes by providing feedback
  - Support by patient organizations

- Healthcare providers or mainstream telecomm providers (B2B approach)
  - as clients (or even buyers of the whole mHealth company).

- Health authorities as direct interlocutors of the mHealth companies (B2G approach)
  - as third party data suppliers setting minimum criteria for compliance.

**Channels**

- Online marketplaces for apps
- Apps prescribed as clinical services by health professionals
- Apps tested/validated/recommended by patients associations or healthcare professional societies
- Apps integrated in mainstream devices
- Cross sector collaboration (e.g. services offered by work insurances to expat workers)
Business Canvas for HL7 FHIR IPS: Customer Segments

Citizens, in particular those benefiting of cross border healthcare services:
✓ Tourists
✓ Chronic patients
✓ Expat workers

Healthcare professional associations (e.g. EU Society of Hypertension, etc.)

Healthcare provider organisations (e.g. hospital, primary care provider)

Insurers

Patient advocacy organizations

Medical tourism / hospitality organizations

Other digital health companies and EHR/PHR/HIS software providers
Business Canvas for HL7 FHIR IPS: Cost Structure

The Cost Structure is:

✓ **value driven**, thus less concerned on cost minimization and more focused on value creation by enhancing the services offered by the app incorporating the IPS;

✓ **economies of learning**, meaning here that incorporating the IPS gives them the opportunity to know in advance the key information to be searched for and its format and may access to a set of resources such as training, servers, and tools provided by the SDOs which reduce considerably their R&D and integration costs.

Main categories of costs are

✓ software development;
✓ integration costs;
✓ training;
✓ personal assistance and software maintenance;
✓ certification;
✓ standardisation training and
✓ membership fees.
Revenue Streams: Key types of revenues envisaged for mHealth companies are:

- Subscription/download fees following e.g. medical prescription of the mHealth app
- Recommendations formulated by patients associations or healthcare professionals societies

Usage fees:

- Agreements with healthcare providers, insurers to outsource development of apps
- Acquisition by mainstream devices or OEM Revenue sharing on end to end services
Reported Electronic Exchange of Child Health Data

• MOCHA reviewed cases of urgent health care in schools, conducted interviews, compiled use cases
• MOCHA considered children autonomy from treatment, health record access by children and guardians
• MOCHA Identified cases of data messages or structured data transfer:
  • At birth to primary care practices (Den, Est, Hun, Ice, Ire, NL, PT, ES)
  • Over concerns of possible child maltreatment (NL, PT)
  • On discharge from hospital (other than birth) (Den, Est, Ice, NL, PT, ES)
  • Concerning preventive health/routine exams (Den, Est, NL, PT)
  • Concerning immunologists (HR, Den, Est, Ice, Ire, NL, No, PT)
  • At birth to home visiting nurses (Den, Est, Hu, Ice, Ire, NL, PT, ES)
School Health records and Data sharing with primary care

- Estonia: 1
  - Details of all child/patient contact and activity
  - There is a policy not to pass information between SHS practitioners and primary care practitioners

- Netherlands: 1
  - Screening results and immunisations
  - Only significant events (examples: child protection concern, accidental injury, repeated loss of consciousness (e.g. fainting))

- Denmark, Estonia, France, Iceland, Poland, Portugal, Romania: 7
  - Screening results and immunisations
  - Only significant events (examples: child protection concern, accidental injury, repeated loss of consciousness (e.g. fainting))

- Denmark, Estonia, Greece, Iceland, Ireland, Lithuania, Portugal, Slovenia, United Kingdom: 9
  - Only significant events (examples: child protection concern, accidental injury, repeated loss of consciousness (e.g. fainting))

- Austria, Croatia, Cyprus, Hungary, Ireland, Italy, Latvia, Malta, Norway, Romania: 10
  - There is no policy as to what information should be passed between SHS practitioners and primary care practitioners

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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
Timelines

**CEN/TC251**
- prEN 17269
  - ballot passed
- DTS 17288
  - ballot passed
- Ready for publication on March 2019

**HL7**
- HL7 CDA IPS IG (STU)
  - published
- HL7 FHIR IPS IG (STU)
  - ballot passed
  - expected publication begin 2019

**SNOMED Int.**
- IPS Free Set (provisional)
  - Content finalised - January 2019
  - Available to be added to specifications at drafting stage – February 2019
  - Publicly available from SNOMED International – June 2019

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Digital Health and Wellness Summit, MWC2019
Building blocks of the International Patient Summary standards and beyond

**HL7® FHIR®**

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The Trillium II data set (based on prEN 12679)

https://art-decor.org/art-decor/decor-datasets--trilm2-
The FHIR IPS IG (STU)

https://build.fhir.org/ig/HL7/fhir-ips/

Based on FHIR R4
(Published on January 2019)

It describes the “IPS document” and the data blocks (FHIR profiles) used to build it
The Trillium II IPS FHIR Profiles

Based on FHIR STU3

It describes the “IPS document” and the data blocks (FHIR profiles) used to build it

https://simplifier.net/TrilliumII/~resources?category=Profile
The Trillium II IPS FHIR Profiles

https://github.com/gcangioli/trilliumII

All the source files for HL7 FHIR Profiles specified HL7 FHIR Value Set examples
Useful Links

- [https://simplifier.net/TrilliumII/](https://simplifier.net/TrilliumII/)
  - [https://simplifier.net/TrilliumII/~resources?category=Profile](https://simplifier.net/TrilliumII/~resources?category=Profile)
  - [https://simplifier.net/TrilliumII/~resources?category=Example](https://simplifier.net/TrilliumII/~resources?category=Example)
  - [https://simplifier.net/TrilliumII/~resources?category=Extension](https://simplifier.net/TrilliumII/~resources?category=Extension)
- [https://art-decor.org/art-decor/decor-project--trilm2-](https://art-decor.org/art-decor/decor-project--trilm2-)
  - [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-)
- [https://github.com/gcangioli/trilliumII](https://github.com/gcangioli/trilliumII)