

## HL7 FHIR and the International Patient Summary



eHAction  
Roadmap



### **Ownership and content**

HL7 International Foundation  
(European Office of HL7)  
Square de Meeûs 38/40  
1000 Brussels  
Belgium

E-mail: euoffice@hl7.org  
Website: www.hl7.eu Wiki: wiki.hl7.eu

### **Concept, design and realisation**

Heitmann Consulting and Services | Max-Ernst-Str. 11 |  
50354 Hürth, Germany

E-Mail: info@heitmann-cs.com  
Website: www.heitmann-cs.com

LUP AG | Filzengraben 15-17 | 50676 Köln, Germany

E-Mail: info@lup-ag.de  
Website: www.lup-ag.de

### **Photography**

Adobe Stock: © godfather744431 (p1), © botond1977 (p1),  
© thodonal (p6), © elenabsl (p15), © Ray (all flags)  
© Focus Features/Tohokushinsha Film (p34)  
All other images are copyright to their respective owners.

### **Copyright**

Copyright © 2019 Health Level Seven International  
3300 Washtenaw Avenue, Suite 227  
Ann Arbor, MI 48104  
USA

E-mail: HQ@hl7.org  
Website: www.hl7.org

All rights reserved!

# Contents

Support to enabling the digital transformation of health and care in the Digital Single Market	4
Standards help to engage with users of all age groups	6
Trillium-II: Imaging Results in the International Patient Summary	8
HL7 in Denmark: for the benefit of the patient	9
Positioning the International Patient Summary (IPS)	12
Trillium II & IPS : Why and how patient summaries sharable within and across borders incorporate lab results	14
European Innovation Partnership Active and Healthy Aging (EIP-AHA) Reference Site Collaboration Network	16
FAIR4Health: Improving Health Research through FAIR Data	18
SurPass-IPS: Delivering on the social value of health data for Childhood Cancer Survivors	20
Citizen and Health Data – adding opportunities for personalization	22
RDCODE	24
Interoperability of Regional EHR systems in Italy: the contribution of HL7 Italy	27
Success with telemedicine for pregnant women with complicated pregnancies	29
Patient Summaries in the FrailSafe Ecosystem	31
Preserved in translation	33
eHAction Roadmap for future eHealth Digital Services Infrastructure: Use Cases and Features	35
Enabling Integrated Care for Chronic Disease Patients with the Help of International Patient Summaries	37
HL7 FHIR IPS in a CDISC World: Expanding the Patient Summary Ecosystem	39
Digital Health Systems of the Future	41
Digital Transformation of the Healthcare and Social Welfare Services in Finland	43
Bridging the Gap – engaging doctors and health care professionals in eHealth	46
How to make sure your patient summary can be shared	47
The Joint Initiative Council: International Collaboration for Digital Health Standards	49
Electronic Health Record Exchange Format (EHRxF)	50
HACKING HEALTH Athens has HL7 FHIR IPS as its central theme	52
FORTH and University of Crete win the first prize at Hacking Health in Athens!	55
EU MODEX Estonia: Patient Summaries in Disaster Management	58



# Support to enabling the digital transformation of health and care in the Digital Single Market

In May this year the Digital Single Market Strategy [1] will celebrate its fourth birthday. One of its main goals is to ensure that citizens and businesses can take full advantage of the opportunities digitization can offer.

Digitalizing the EU healthcare industry poses a significant challenge, with different healthcare systems, standards and practices being in place across European countries. At the same time, the transformation of health and care in the Digital Single Market will bring about significant benefit to people, health care systems and the economy. Digital technologies such as 4G/5G mobile communication, artificial intelligence or supercomputing offer new opportunities to transform the way we receive and provide health and care services. They enable innovative approaches to independent living or integrated health and social care. Health data and advanced data analytics can help accelerate scientific research, personalized medicine, early diagnosis of diseases and more effective treatments [2].

A Communication by the European Commission was published in May 2018 [3] and endorsed by all Member States, outlining the Commission's



by Veli Stroetmann and Strahil Birov



targeted response to three key priorities for advancing the digital transformation of health and care:

- Citizens' secure access to their health data, also across borders - enabling citizens to access their health data across the EU;
- Personalized medicine through shared European data infrastructure - allowing researchers and other professionals to pool resources (data, expertise, computing processing and storage capacities) across the EU;
- Citizen empowerment with digital tools for user feedback and person-centred care - using digital tools to empower people to look after their health, stimulate prevention and enable feedback and interaction between users and health-care providers.

The Communication and its accompanying policy documents provide direction to EU activities in this field for the coming years.

To support the priorities, the European Commission has launched the EU support project DigitalHealthEurope [4]. It will provide comprehensive, integrated and centralised support to the activities defined in the Communication. The project's approach involves actions that will boost innovation and advance all three priorities. To achieve this, the project work plan offers two forms of support [5].

### **Support to large-scale deployment of digital solutions for person-centred integrated care**

DigitalHealthEurope has at its forefront the deployment of digital solutions for person-centred integrated care. Assessment tools will be used to identify, analyze and select successful initiatives which are highly impactful and replicable. Structured advice on EU funding instruments and financing sources will also be given. The selected initiatives will have the opportunity to pursue replication and scaling-up. This will be done with the aid of instruments such as match making and a twinning support scheme. A deployment support service will be developed: it will include guidelines, checklists and documented successful approaches. These results will contribute to capacity building. They will help define the "building blocks" for the scaling-up of innovative practices. The new resources will be widely disseminated. The aim is to encourage even wider uptake of twinned innovation and the assimilation of lessons learned.

### **Support to digital innovation through collaboration platforms**

DigitalHealthEurope will also facilitate the creation of collaboration platforms that directly address the three priorities. Each platform will consist of two complementary levels:

- a policy level to support collaboration agreements, the drafting of recommendations, and a common agenda
- an expert level to foster the elaboration of agreements, needs and actionable recommendations, that guides and informs decisions pursued at the policy level.

To kick-off its activities, DigitalHealthEurope organized two workshops on 20-21 March under the umbrella of the Portugal eHealthSummit in Lisbon. Stakeholders representing governments, industry, academia and patient associations, were invited to weigh in on the EC priorities and to inform DigitalHealthEurope's workplan. Standardization is a key topic across the three priorities, requiring the input of standards development organizations. HL7 participated in the workshops and will support DigitalHealthEurope through its Secretary General, Catherine Chronaki, being a member of the DigitalHealthEurope Board of Experts.

DigitalHealthEurope is a coordination and support action which was launched on 1 January 2019. It will work over a two-year period with a 17-member consortium supported by more than 50 associated experts. If you would like to contribute to the digital transformation of health and care, register at <https://digitalhealtheurope.eu/participate.html> to stay informed about the project's activities and opportunities for involvement.

*Veli Stroetmann and Strahil Birov*

*empirica Technology Research*

For further information visit or contact:

dhe@empirica.com

[digitalhealtheurope.eu](http://digitalhealtheurope.eu)

### **References and further information**

- [1] [https://ec.europa.eu/commission/priorities/digital-single-market\\_en](https://ec.europa.eu/commission/priorities/digital-single-market_en)
- [2] Transformation of Health and Care in the Digital Single Market, <https://ec.europa.eu/digital-single-market/en/european-policy-ehealth>
- [3] EC COM(2018)233
- [4] <https://digitalhealtheurope.eu/>
- [5] <https://ec.europa.eu/digital-single-market/en/news/digitalhealtheurope-get-support-your-digital-transformation-health-and-care-activities>



# Standards help to engage with users of all age groups



by Fernando Machicado



*Demographics are changing. The proportion of people aged 65 and above was almost 30% in 2016 in the European Union (EU) relative to those aged between 15 and 64. It will increase to more than 50% in 2070 [1].*

Older people are an important and growing group of stakeholders in Europe. Standards, regulations, guidelines, specifications and interoperability profiles, can play an important role in making sure that products and services respond to the needs and choices of older people.

The role and input of societal stakeholders in the development of standards is being strengthened, by reinforcing the support of organizations representing citizens [2]. Examples include consumers' representatives (ANEC), trade unions (ETUC), environmental citizens' organizations (ECOs) as well as small- and medium-sized businesses (SBS).

Standards organizations have a crucial role in reaching this objective. Today, the three European Standards Organizations (ESOs), i.e. CEN, CENELEC and ETSI, are facilitating the appropriate participation of all relevant stakeholders. Associations like HL7 can surely strengthen this trend.

The European Union-funded project PROGRESSIVE [3] has helped to create a STAIR-AHA platform under the umbrella of CEN-CENELEC.

On 31 January 2019, the platform developed a statement that outlines recommendations for the need for change in developing standards for active and healthy ageing.

The statement is grounded in the findings, discussions and conclusions of two earlier STAIR-AHA meetings [4], both organized by the PROGRESSIVE project [5]. In addition, the online platform founded by the PROGRESSIVE project and associated PROGRESSIVE reports, may provide useful support materials to standardizers that are aiming to involve older adults in their work [6].

The statement's eight recommendations follow:

**1** International, European and national **standardization bodies** wishing to be relevant for ageing societies in their approaches to standardization should base their work on the following non-exhaustive list of key ethical tenets:

- Accessibility and Usability
- Affordability

- Autonomy and Empowerment
- Beneficence and Non-Maleficence
- Care, Protection and Support
- Equality, Equity, Justice
- Inclusion, Non-Discrimination, Social Impact
- Interoperability
- Privacy, Safety, Security

**2** International, European and national standardization processes should be revised to ensure that they enable the participation of older people's representatives, as a relevant group of stakeholders, to initiatives that concern them most.

**3** International, European and national standards organizations should be encouraged to reach out to underrepresented groups of citizens and solicit their opinions on relevant questions. Creative user coproduction methodologies should be implemented, as a tool to engage all end-users in the standardization process. Specifically, STAIR-AHA recommends promoting the use of the Guidelines for User Co-production in Standards developed by the PROGRESSIVE project [7].

**4** The existence of forums of discussion for the dissemination, awareness and discussion of issues related to active and healthy ageing standardization, engaging experts from a broad spectrum of stakeholders' groups such as the CEN-CENELEC STAIR-AHA platform, should be promoted.

**5** The awareness of end-users of the benefit of standards and the relevant role they have in the definition of quality products and services, as well as how they can contribute to standards development, should be increased. The awareness of the mutual benefits of the inclusion of older people's needs in standards, products and services for both older people and standards organizations should be raised.

**6** The promotion of the participation of older people's representatives in standardization should be encouraged at the national level of standardization bodies, because – at that level – it enables debate that is closer to the language of the stakeholders.

**7** The design and use of technology that supports services for older people should be made

**transparent** to end-users, since the accessibility and usability of environments – both built and digital – are key issues in ensuring the participation of a wide range of citizens.

**8** Standardizers, policy-makers and socio-economic actors involved in standardization may find various reports and deliverables produced by the PROGRESSIVE project to be useful in supporting the future work to be done on including older people in the process of standardization design and implementation. These include guidelines on standards covering age-friendliness; smart homes for older adults; and interoperability frameworks [8].

*Fernando Machicado  
Responsible for Stakeholder Engagement  
UNE - Asociación Española de Normalización  
Madrid (Spain)*

- [1] The 2018 Ageing Report: Economic and Budgetary Projections for the EU Member States (2016-2070). [https://ec.europa.eu/info/news/economy-finance/policy-implications-ageing-examined-new-report-2018-may-25\\_e](https://ec.europa.eu/info/news/economy-finance/policy-implications-ageing-examined-new-report-2018-may-25_e)
- [2] Regulation (EU) No 1025/2012. <https://eur-lex.europa.eu/legal-content/EN/TXT/?uri=celex%3A32012R1025>
- [3] <https://progressivestandards.org>
- [4] The report of the meetings are available at [https://progressivestandards.org/wp-content/uploads/2019/02/1st-STAIR-AHA-DRAFT-meeting-report\\_V\\_0\\_6.pdf](https://progressivestandards.org/wp-content/uploads/2019/02/1st-STAIR-AHA-DRAFT-meeting-report_V_0_6.pdf) and [https://progressivestandards.org/wp-content/uploads/2019/03/2nd-STAIR-AHA-meeting-report\\_V\\_0\\_3.pdf](https://progressivestandards.org/wp-content/uploads/2019/03/2nd-STAIR-AHA-meeting-report_V_0_3.pdf)
- [5] More information about the STAIR-AHA can be found online: <https://progressivestandards.org/wp-content/uploads/2018/10/PROGRESSIVE-Factsheet-STAIR-AHA.pdf>
- [6] For the PROGRESSIVE online platform, see: <https://progressivestandards.org>
- [7] The "Guidelines for user co-production in standards" developed by the PROGRESSIVE project are available at [https://progressivestandards.org/wp-content/uploads/2018/08/PROGRESSIVE-guide-on-user-co-production\\_20180606.pdf](https://progressivestandards.org/wp-content/uploads/2018/08/PROGRESSIVE-guide-on-user-co-production_20180606.pdf)
- [8] See: <https://progressivestandards.org/resources/project-reports/>

# Trillium-II: Imaging Results in the International Patient Summary



by Marco Eichberg



The EU funded Trillium-II project<sup>1</sup> has the objective of scaling up the EU/US cooperation initiated with the successful Trillium Bridge project by advancing the adoption of the International Patient Summary (IPS) standard and implementation guide (see Newsletter 08/2018) and by examining new use cases beyond emergency and unplanned care, for which the IPS was originally designed.

One of the elements examined in detail by Trillium-II is how information resulting from imaging procedures could be represented in the IPS, which may be important for example in summaries supporting the continuity of care when patients have to undergo treatment at different institutions.

The imaging results component of a patient summary encompasses on one hand diagnostic observations based on medical imaging procedures such as X-ray, CT, MRI, Ultrasound etc., which often include measurements such as diameters, volumes or velocities, and on the other hand references to the set of medical images on which the diagnostic observations were based. Imaging results in a patient summary do not represent a diagnostic report, however, nor a part of a diagnostic report. They are a set of selected observations of clinical significance for future care to the patient from one or more existing reports.

Our team started the design of the imaging results component with an analysis of the information models represented in existing standards for diagnostic imaging reports, including various HL7 CDA templates, the DICOM Basic Diagnostic Imaging Report, OpenEHR archetypes and several HL7 FHIR resources such as the DiagnosticReport. We then designed a comprehensive but very complex information model that could represent the information from all of these sources. This initial design was then simplified, based on an assessment of the relevance of the different parts of the information model for a patient summary, into a refined information model, which exists in a basic and a comprehensive form with different requirements on element presence and cardinality.

Value sets for coded elements were identified or designed in ART-DECOR, and a mapping of the abstract information model to FHIR STU3 resources was developed and used with a number of sample reports in order to validate the feasibility of the concept. Some of the guiding considerations are:

- The selection of content for a patient summary is a trade-off between the aim to provide a precise medical view of the patient's current condition and the necessity to build an efficient summary, actionable by any new care provider unexpectedly encountering the patient. This balance remains the ultimate choice of the author(s) of a summary, based on the summary's purpose.
- The workflow information that is essential in a diagnostic report, such as the reference to the order that a report fulfills, identification of the requester, the reason for requesting, the time of request, etc. are in general not of interest in a patient summary.
- In a patient summary, like in a diagnostic imaging report, output observations are actionable for future care only if they are qualified by their context. In this sense, the knowledge of who interpreted the diagnostic evidences the reported results refer to (the "observer") is relevant.
- A diagnostic imaging report usually describes observations that belong to one diagnostic study (one requested procedure). In a patient summary, however, imaging observations may be grouped following different criteria, for example: same study, same problem, and same type of examination.

Another important question to be considered is how access to the original images can be provided. All standardized document formats for diagnostic imaging reports have in common that the original images, which may be very

large in volume (up to several GB per study) are referenced and not included. While access to images within an institution is easy to organize, cross-enterprise or even cross-border access is a much more complex topic, since issues such as a federated user authentication, management of access rights, management patient consents and, of course, IT security issues have to be considered. The most relevant standard in this field is the IHE Cross-Community Access for Imaging (XCA) profile, but other standards such as HL7 FHIR DocumentReferences need to be considered as well.

In summary, the authors believe that the extension of the IPS with imaging results enhances the usability of patient summaries for additional use cases. Readers interested in further details can access the full documentation (D3.5) at <https://trillium2.eu/deliverables/>.

*Dr. Marco Eichelberg,  
OFFIS-Institute for Information Technology, Germany*

## References

- [1] Trillium-II project, [www.trillium2.eu](http://www.trillium2.eu)



# HL7 in Denmark: for the benefit of the patient

*For the last decades, Denmark has focused on offering world-class digital solutions to enhance the existing healthcare services, and today Denmark ranges among a few HL7 top-performing countries in the world. This is primarily due to the homogeneity of the Danish healthcare sector where most hospitals are public, and the primary care is well regulated as an integral part of the overall healthcare ecosystem. On this foundation, a number of digital solutions have been developed which allow citizens easy access to a number of digital healthcare services. All citizens have access to their own medical and immunization record, journals from public hospitals and much more.*

The overall philosophy is simple. We aim to give patients the best possible treatment, and therefore it is crucial for healthcare professionals, the patients and their relatives to share and have access to all relevant information – even across sectors, public and private domains and healthcare providers.

When in 2015, the Danes were asked what the number-one contributor to an improved healthcare system would be, the answer was clear:



by Morten Wiese and Anders Brahm



A vast majority pointed to greater coherence between the different sectors of the healthcare system as the number one area of improvement.

When all relevant information about the patient is readily available to the healthcare professional, focus can be on dialogue and providing the optimal care and treatment instead of re-collecting already accessible data. The patients will experience a more qualified and flexible interaction with the healthcare professionals where the dialogue can centre on a better assessment and treatment of the patient's condition. Furthermore, the patient's interaction with the healthcare system might be able to take place in the patient's home with the



aid of digital telemedicine solutions, which adds obvious practical benefits for the patients but also allows the patient an opportunity to follow and master their condition(s) without unnecessary interaction with the healthcare system.

The National Strategy for Digital Health was launched in 2018 (see <https://www.sum.dk/Aktuelt/Publikationer/A-Coherent-and-Trustworthy-Health-Network-for-All.aspx>). The strategy defines five focus areas in order to achieve the objectives of putting patients' needs first and making the daily workflows easier for healthcare professionals. One of the focus areas is to develop an ecosystem of services and components. Even if this is not directly related to the delivery of primary care, it is considered a precondition for achieving the overall strategic goal of boosting the collaboration of our many different IT-systems and exchanging relevant information by using common digital standards.

So what exactly are the major initiatives we are working on these days to improve healthcare by bringing data to the right people at the right time?

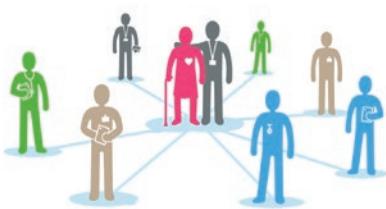
## The Unified Patient Overview

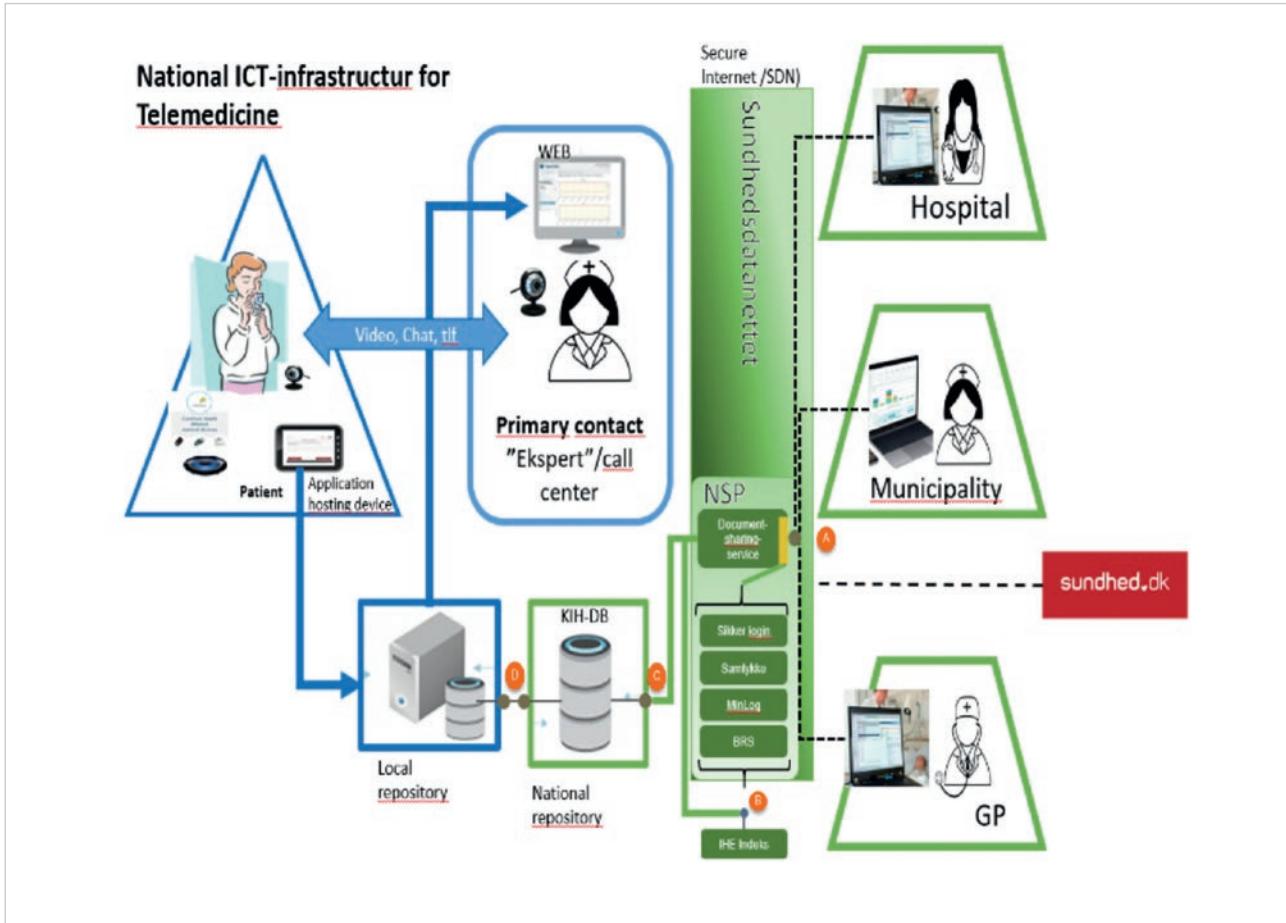
The unified patient overview (UPO) covers all general information relevant for the patient's care and treatment. The first two parts of the UPO cover basic information about the patient called the patient summary, the patient's appointments and the patient's care plan. The patient summary and the appointment overview are currently being tested by clinicians in the Northern and Central Regions of Denmark, as well as in the municipalities of Aarhus and Frederikshavn together with selected GPs within the regions. After testing, the goals is a nationwide implementation by the end of 2020. The unified patient overview gives the patients and their relatives a better overview of their own patient pathway and makes it easier for employees across the healthcare system to provide a better, more coherent and coordinated care. The UPO is based on Danish profiles of HL7 CDA standards, where the appointment overview is based on HL7 CDA Appointment Document (DK APD). The patient summary is based on a modification of the HL7 CDA profile.

## Telemedicine and Patient Reported Outcome (PRO)

For the last two years, all 98 municipalities and the 5 regions of Denmark have joined forces to establish a common telemedicine solution for patients suffering from COPD. The telemedicine solution for COPD will build on core national infrastructure and common standards thus, making sharing of data generated by the patients easier and more accessible to relevant healthcare professionals. The Danish national telemedicine infrastructure uses the Danish profile of the HL7 CDA Personal Healthcare Monitoring Report (PHMR-DK) as the mandatory format for exchanging data.

Across the healthcare system, a wide range of activities has been launched aimed at implementing Patient Reported Outcome (PRO) initiatives. PRO is a general designation for patient's responses to questions about their own state of health. By using PRO systematically and actively in the dialogue with the patient, the healthcare system's actions can be personalized to meet individual needs and support value-based health. The answers may also be used to screen for side effects and consultation needs, so the patient avoids unnecessary check-ups. At the same time, PRO creates an abundance of new data for research and quality improvement. Used correctly, PRO will be just as essential to the quality of





treatment as clinical data. The value of PRO should therefore not be underestimated but should be conceptually interpreted with the same importance as clinical data.

A national PRO office has been challenged with the task of developing a series of standardized PRO questionnaires to be used across the Danish healthcare sector. Clinicians validate the questionnaires and they will be technically available in a national questionnaire database. The

questionnaires will be shared through the national infrastructure by using the Danish profile for HL7 CDA questionnaire form definition and response document (DK-QFDD and DK-QRD).

*Morten Wiese, Anders Brahm  
Danish Health Data Authority*



# Positioning the International Patient Summary (IPS)

The IPS Project has achieved far more than we had any right to expect! Consider the likelihood of two standards developing organisations (SDOs) working together on a topic as old as the hills, and just as common place, making considerable progress on a global stage, and creating four new, coherent and consistent standards within two years, with successful balloting and certain publication of all four within three years! Surprising but true.

The IPS Project was/is essentially a very successful partnership between CEN/TC251 and HL7; two SDOs that in the past have often disagreed or simply gone their own way; each with its own organisational culture that has resulted in different ballot cycles, different stakeholder engagement, and different policies. However, it is not the first time that collaboration has worked. In 2007, TC251 and HL7 (the third collaborative party being ISO/TC215) are credited with creating the Joint Initiative Council (JIC), which has also played a role in promoting the patient summary work.

The Council was charged with opening up dialogue between the SDOs and created a membership Charter to make a public statement of intent. In part, JIC was formed to answer the dissatisfaction from stakeholders at, what they saw as, duplication with the associated multiplying effect of having too many standards often covering the same areas and creating a mess of choice for the would-be commissioners and developers. At that time, interoperability solutions were not perceived as being served by the SDO activities, rather it seemed to many observers that they were making matters worse by overcomplicating an already complex field of endeavour with non-harmonized, inconsistent standards. JIC is not a formal standards developer in its own right but it has grown to encompass main-stream standards and profiling organisations in the Health Informatics domain, working in the background to restore credibility to the idea of 'joined-up' approaches.

Fast forward to 2015, JIC proposed the idea of creating informative guides as a public service and as away of attracting attention to its ongoing



by Stephen Kay



activities. JIC launched the San Francisco Declaration in April, "The JIC will contribute to better global patient health outcomes by providing strategic leadership in the specification of sets of implementable standards for health information sharing." [1]. The Patient Summary was chosen as the first topic, because it was clear that there was already considerable interest and consequently several initiatives underway across the world. This was particularly true in America and Europe where a Memorandum of Understanding was established for EU-US cooperation. Some of these activities already involved both CEN/TC251 and HL7, who were acting separately in projects on Patient Summary Standards.

CEN IPS was a TC251 proposal made to the European Commission in 2015; the actual work started in September 2016. It had two principal strands; the first was to enable a team of five, comprising an administrator and four technical experts, to participate in International activities on Patient Summary standardization and the second was to formalise the existing guidelines from Europe, turning them into an international standard. This second part may seem to have been a tall order, but a critical success factor was that the European guideline was already a basis for substantive work in Europe, as well as in the HL7 INTERPAS project, and was referenced too by the JIC guidance document.

The European project Trillium II [2] facilitated a meeting between the two SDOs in Oslo in April 2017, where we established a common vision, mission and scope for the International Patient



Figure 1: <http://bit.ly/IPS-Discover>

Summary with CEN IPS and HL7 IPS cementing their effective and successful collaboration [3]. The rest, as they say, is history. It is, nevertheless, worth noting that:

- The International Patient Summary is not only for cross-border care, but can equally support the exchange at local, national and regional levels.
- The International Patient Summary Project's thinking has evolved. The IPS is now also perceived as a catalyst and model for a toolkit to be used in a variety of different circumstances, selecting and extending the IPS data blocks for each individual use case.

The four IPS Specifications have been created, balloted, all ahead of schedule, and all this was done by each SDO playing to its strengths rather than competing. What is more, with the new deal between HL7 International and SNOMED CT, and the intention of CEN to move the IPS Dataset into ISO, the IPS collaboration can be seen as the practical embodiment and value of the joined-up philosophy of JIC. CEN IPS had its final funded stakeholder meeting in Brussels on March 19th, 2019.

All that having been said, we are now at the beginning of joint IPS development rather than at its ending. The dataset specification will be refined and it will mature in an incremental, planned way to give confidence of stability to the vendor and maintain relevance for the healthcare communities.

The creation of beautiful, consistent specifications is one thing. SDOs now need to position the IPS for acceptance, for adoption and for real use, and so must find effective and efficient forms of dissemination, of sustainable development and, last but not least, of productive governance:

- Dissemination has been an on-going part of the IPS Project from its inception, where the CEN and HL7 teams have presented, written and explained what the IPS is, what it can do, and

why it is so important. One attempt to capture this story, and to ensure the compelling arguments and rationale are not lost, is the CEN IPS Prezi (see Figure 1 and URL), which is intended to complement and showcase the normative standards; for IPS to have the intended impact, the story and standards must address multiple audiences, as only a relatively few will avidly read the specifications!

- The UN [4] defines 'Sustainable Development' as development that "meets the needs of the present without compromising the ability of future generations to meet their needs". We believe that the IPS approach offers that opportunity; we should not squander it if we wish IPS, and initiatives modelled on it, to have a future; one that will benefit us, both as individuals, i.e., potential subjects of care needing a good quality summary and, more generally, as joint beneficiaries from establishing better continuity and coordination of healthcare.
- The IPS Project began work as a collaborative of two SDOs, but has since attracted others, who see value in the collaboration and outcome, and each with a specific role to play going forward. The Trillium II deliverable [5] on the IPS governance suggests a future, potential role for JIC; it is our mission then - should we choose to accept it.

*Stephen Kay Ph.D., M.Sc., FBCS, FACMI  
Project Leader of CEN IPS*

## References

- [1] JIC, <http://www.jointinitiativecouncil.org/>
- [2] <http://www.estandards-project.eu>
- [3] CEN/TC 251 & HL7 Agreement to IPS collaboration, 2017, <http://bit.ly/IPS-Oslo-agreement>
- [4] United Nations. 1987. "Report of the World Commission on Environment and Development." General Assembly Resolution 42/187
- [5] Stegwee R, Trillium II Deliverable. 2019, WP5, D5.2 Towards an international patient summary standards Governance Framework: managing requirements, intelligence gathering, and updates (an abstract appears in this newsletter).

# Trillium II & IPS : Why and how patient summaries sharable within and across borders incorporate lab results

Playing a predominant role in the diagnosis, prognostic and follow-up surveillance of health problems, laboratory results are shared in a meaningful way among healthcare providers in two main kinds of situations:

**1** Within the care team cooperating on the current episode of care for the patient. "Care team" is to be interpreted here in a broad sense, and includes the family doctor who referred the patient to a healthcare institution, the caregivers and ancillary services of this institution, as well as the external laboratories, clinics, imaging centers, community pharmacies, nurses, therapists ... that may contribute to the care delivery for this episode. In this context, result reports of laboratory medicine and anatomic pathology, often play a role of paramount importance in establishing the diagnostic (e.g. histopathology of a cancer) as well as monitoring the patient condition during post-treatment follow-up (e.g. molecular or antigen tumor marker testing after a chemotherapy).

**2** As part of electronic longitudinal records consolidated across care episodes. Summaries of these longitudinal records need to be assembled for the sake of care continuity and made available to new care providers met by the patients in their own country as well as abroad. Selected laboratory results play their role in such electronic health record summaries, providing for instance the last six months of HbA1c level measurements for a chronic diabetic patient, or of INR for a patient at risk of thrombosis undergoing a long course anti-vitamin K treatment, or warning future care providers about a healthy carrier of a multi-drug resistant bacterium.

For the first "episode-centric" situation, the full laboratory report is needed. An interoperable standard format for clinical laboratory reports, based on the HL7 CDA standard, specified by IHE



Francois Macary, Chair HL7 France



International in 2008 as the XD-LAB profile, has been selected in 2013 by the eHealth European Interoperability Framework, and is adopted in a number of European countries like France, Austria, Belgium, Switzerland, Italy. More recently, IHE has also published a standard format for pathology reports, APSR 2.1, also based on CDA R2.

The second "continuity-of-care" situation encompasses use cases such as emergency and unplanned care, continuity of care to persons affected by chronic diseases, disaster management, and other cases where a person needs to be attended by new care providers, possibly speaking a different language. In this kind of situations, a summary of the person's health record, assembling the key information about their health and current treatment, interpretable in the language of the local caregiver, is needed. Such an electronic health record summary may be retrieved on the cell phone of the patient or of the caregiver. It must present at first glance the most important facts about the person's health, that the new caregiver needs to be made aware of immediately. This patient summary must also offer the capability to the caregiver to dig out more details as needed on particular topics, for instance unfolding the latest laboratory test results monitoring the patient's chronic condition, or bringing up the summary of a hospital encounter during which



the patient coronary artery stent was implanted, or retrieving the conclusion of the pathology report, which diagnosed a tumor. Such a multi-lingual health record summary, organizing data in successive layers from a top synthetic view down to more granular details, needs to leverage a state-of-the-art standard, more flexible and dynamic than CDA R2. Therefore, the EU-funded Trillium II project set up in 2017 to tackle with this family of situations has built its international patient summary upon the “Fast Health Interoperability Resource” (FHIR) standard, which is the latest standard produced by HL7 International and the best fit to fulfill such flexibility requirements. Among the FHIR building blocks selected and constrained by Trillium II, is the set of FHIR resources designed to convey diagnostic results. Trillium II has defined a set of constraints to convey laboratory medicine results, and another set for anatomic pathology results.

Scaling up the cooperation between EU and US on sharable international patient summaries initiated in 2013-2014 with Trillium Bridge, the Trillium II project has been driven in close coordination with the HL7 International / CEN TC 251 standardized “International Patient Summary” (IPS) project, so that the Trillium II implementation of a patient summary be based on the HL7/CEN IPS FHIR implementation specifications, extending them where needed, to cover the broader set of use

cases that Trillium II addresses. Thus, the final deliverable of Trillium II to be released end of June 2019, will provide a complete library of standardized digital assets conforming to the European standard EN 17269 for an IPS dataset and constraining the HL7 FHIR standard. As a side effect, these deliverables of this Horizon 2020 project are expected to be also used as input into the elaboration of a European electronic health record exchange format, called by a European Commission recommendation issued on February 6, 2019.

*Francois Macary, Chair HL7 France*

# European Innovation Partnership Active and Healthy Aging (EIP-AHA) Reference Site Collaboration Network

The Reference Site Collaboration Network (RSCN, [www.rscn.eu](http://www.rscn.eu)) brings together all European Innovation Partnership on Active and Healthy Ageing Reference Sites across Europe into a permanent forum to promote cooperation among regions. It plays a crucial role in sharing experiences, and developing and promoting areas of innovative good practice and solutions in health and care. The RSCN is a non-profit association, based in Brussels, that creates synergies and shares experiences among the 74 Reference Sites awarded in 2016.

Reference Sites are inspirational ecosystems, delivering creative and workable solutions that improve the lives and health of older people. These solutions can now be scaled-up and replicated across the EU. The Sites are regions, cities, integrated hospitals or care organizations that focus on a comprehensive, innovation-based approach to active and healthy ageing. They offer concrete examples of their positive impact in this field. Reference Sites demonstrate synergies between different actions, breakthrough solutions within a short time frame, and the added value of taking a holistic approach.

With the aim of contributing to the development of policy related to eHealth at EU level in a multidisciplinary approach, the RSCN became a member of the eHealth Stakeholder Group of the European Commission for the period 2016-2018. The network has lead the working group on "Care continuum", and has worked closely with other eHealth Stakeholder Group members to produce a brief report on this topic. Other contributors to this group has been AESGP, CEN, COCIR, EASPD, EFN, EHTEL, ESC, ECHA, HOPE, IHE-Europe and PGEU.

After a short introduction and a description of main concepts, the report focuses on the eHealth elements contributing to improve continuity of care. Different eHealth services are identified as main assets to enhance continuity of care. The initial list of these services includes:



Ana Maria Carriazo, RSCN co-Vice Chair



Providing: Citizens/patients identifier.

Improving access to health care services:

- Appointment booking on line
- Web-based or telephone healthcare information service
- E-referral systems (enabling communication between health professionals)
- Remote consultation
- CT tools enabling communication between patients, formal and informal carers and health professionals

Enhancing care coordination and integration:

- Electronic health records - EHRs
- Personal/Patient health records - PHRs
- Telehealth and telemedicine systems
- MHealth
- Telecare systems
- ePrescription systems
- Decision support systems

## Enabling self-management:

- Telehealth and remote monitoring
- Access to EHRs information
- Computerized systems for care management, health advice and reminders
- mHealth and assistive technologies supporting daily activities in the home
- Health, activity and behaviour monitoring systems
- ICT tools enabling integration of informal and formal care
- Reminders (mobile app).
- Access to online health information including electronic patient information leaflets.

## Health data analytics.

- Risk stratification systems
- Big data and its potential uses such as predictive models, behavioural patterns, new needs identification, risks reduction, personalised care or population models.

The report also considers comments and suggestions, starting with potential barriers to overcome in order to achieve patient-centred care. The following recommendations are considered:

- People-centred care, focusing not only on patients and their diagnosis but on the persons and their individual and collective needs.
- Focus on healthy lifestyles promotion (habits and diet, physical activity).
- Stakeholder engagement.
- Empowering and engaging people (citizens, family, informal carers),
- A balanced approach,
- Sharing information and results, improving communication and coordination.
- Data security and privacy, with the GDPR in place.
- Trust, and create sustainable services demonstrating their added value.
- Health information learning/training, both for citizens and professionals.
- Continuous professional education and skills development.
- Electronic health records, share case work flows, crucial in the context of care continuum and integrated care.
- Conceptual, semantic and technical standards need to be promoted and implemented to allow properly sharing of information and data.

■ Adequate funding and business models, including incentives for facilitating health and welfare professional involvement and collaboration for better health outcomes.

■ Cultural and organizational change, new ways of working are needed as well as new flexibilities.

At the end, the report includes a number of case studies as examples on improvements of continuity of care with the use of eHealth solutions.

The report refers to the European Commission Communication on the digital transformation of health and care in the digital single market, empowering citizens and building a healthier society (COM(2018) 233 final), which set the scene for EU key steps to be followed in this field:

- Citizens' secure access to and sharing of health data across borders;
- Better data to advance research, disease prevention and personalised health and care;
- Digital tools for citizen empowerment and person-centred care.

All of them contribute to a better patient-centred care, improving overall health outcomes.

**The report will be available at [www.rscn.eu](http://www.rscn.eu)**

*Ana Maria Carriazo  
RSCN co-Vice Chair*

## References:

- [1] eHSG subGroup Care continuum  
[https://ec.europa.eu/newsroom/dae/document.cfm?doc\\_id=58929](https://ec.europa.eu/newsroom/dae/document.cfm?doc_id=58929)

# FAIR4Health: Improving Health Research through FAIR Data



The overall objective of FAIR4Health is to facilitate and encourage the European Union (EU) Health Research community to make FAIR (Findable, Accessible, Interoperable and Reusable), share and reuse their datasets derived from publicly funded research initiatives through the demonstration of the potential impact that such strategy will have on health outcomes and health research.

The FAIR4Health vision for year 2020 is a vast, open community of EU health research institutions fully engaged to the Horizon 2020 Open Research Data Mandate enhancing their knowledge-based economy and their research excellence thanks to the application of the FAIR guiding principles. High-quality health research and routine care data will be shared and reused in a secure, controlled and legally compliant environment in order to accelerate knowledge discovery while reducing the bias and enhancing the strength and quality of the scientific evidence raised by the FAIR4Health community members. Furthermore, a community of data scientists from both public research institutions and private companies will be attracted to develop advanced analytical solutions able to communicate with the FAIR4Health platform in order to provide data-driven innovative services that will enable a seamlessly application of the new evidence raised into the clinical practice.

FAIR4Health is coordinated by Prof. Carlos L. Parra-Calderón, head of the Technological Innovation Unit at Virgen del Rocío University Hospital as part of the Andalusian Health Service in Spain. The consortium accounts for 17 partners from 11 EU and non-EU countries. There is a strong representation from both southern and central Europe, and it includes non-EU countries such as Switzerland, Serbia and Turkey.

FAIR4Health gathers expertise from different key domains to address the challenges posed by the project's objectives: Health Research, Interoperability Standards, Research Data Management, Health informatics, Software Development and Legal Framework.<sup>1</sup>

Francisco J. Núñez-Benjumea,  
FAIR4Health Project Manager 

FAIR4Health will design, develop and demonstrate the feasibility of implementing 2 innovative eHealth services based on FAIR data reuse:

- 1** To support the discovery of disease onset triggers and disease association patterns in patients with comorbidities, and demonstrate the reproducibility of such research.
- 2** An innovative prediction service for 30-days readmission risk in complex disease patients.

FAIR4Health will tackle this challenge by addressing it from several perspectives. A comprehensive analysis for FAIR data policy implementation in health research at EU level will be led by University Carlos III of Madrid. This analysis will address current technical and organisational barriers, ethical implications, and security and legal requirements based on several methodologies such as open surveys, bibliography review, focus groups and pop-up research. This comprehensive analysis will inform the development of the FAIR4Health guidelines for FAIR data policy implementation in health research that will be released in collaboration with the Research Data Alliance (RDA) in order to generate specific recommendations on this topic.

Afterwards, HL7 Foundation will lead the work of addressing the FAIR guiding principles to come up with technical solutions for each one of them, including definitions for the Persistence policy of Data FAIRports to be integrated in FAIR4Health.<sup>2</sup> HL7 FHIR will be proposed to support the interoperability framework between all the involved technological components. Management aspects of FAIR (meta)data will be intensively analysed to design technological solutions for de-identification/anonymization, management of different data types, development of consented vocabularies to address data provenance and modelling the FAIR data lifecycle, among others.

In parallel, state-of-the-art Privacy Preserving Distributed Data Mining (PPDDM) techniques will be analysed for the use cases.

This work will inform the development of the technological solution that will support this project: the FAIR4Health platform and agents, task that will be led by Atos Spain. FAIR4Health agents, located at the data owner's premises, will enable the FAIRification of local datasets through its user-driven ETL functionalities. The agents will also host instances of the PPDDM services, so they will run locally. The FAIR4Health platform will support the deployment and delivery of innovative data-driven services to the FAIR4Health community including a repository of actionable PPDDM models. Moreover, the platform will allow for P2P FAIR data sharing under specific licensing agreements. This P2P sharing will be secured from end to end to minimise the risk of disclosing sensitive information while avoiding the execution of malicious services.

Built upon this technology, the University of Geneva will lead the development of the prototypes for the use cases and their prospective demonstration. Both services will be built upon PPDDM methods applied to virtually federated health research and routine care datasets.

Software R&D Consultancy will lead the sustainability of the action, which will be enforced from the beginning of the project (WP6). Targeted key performance indicators will be defined, monitored throughout the project lifespan and

assessed at the end of the project. These indicators will analyse the maintenance of the FAIR4Health platform beyond the project through different mechanisms. This will be assessed based on the adoption of the project outcomes by the FAIR community. Actions beyond the project timeline will consider a marketing strategy for the innovative services developed oriented towards the EU Digital Single Market.

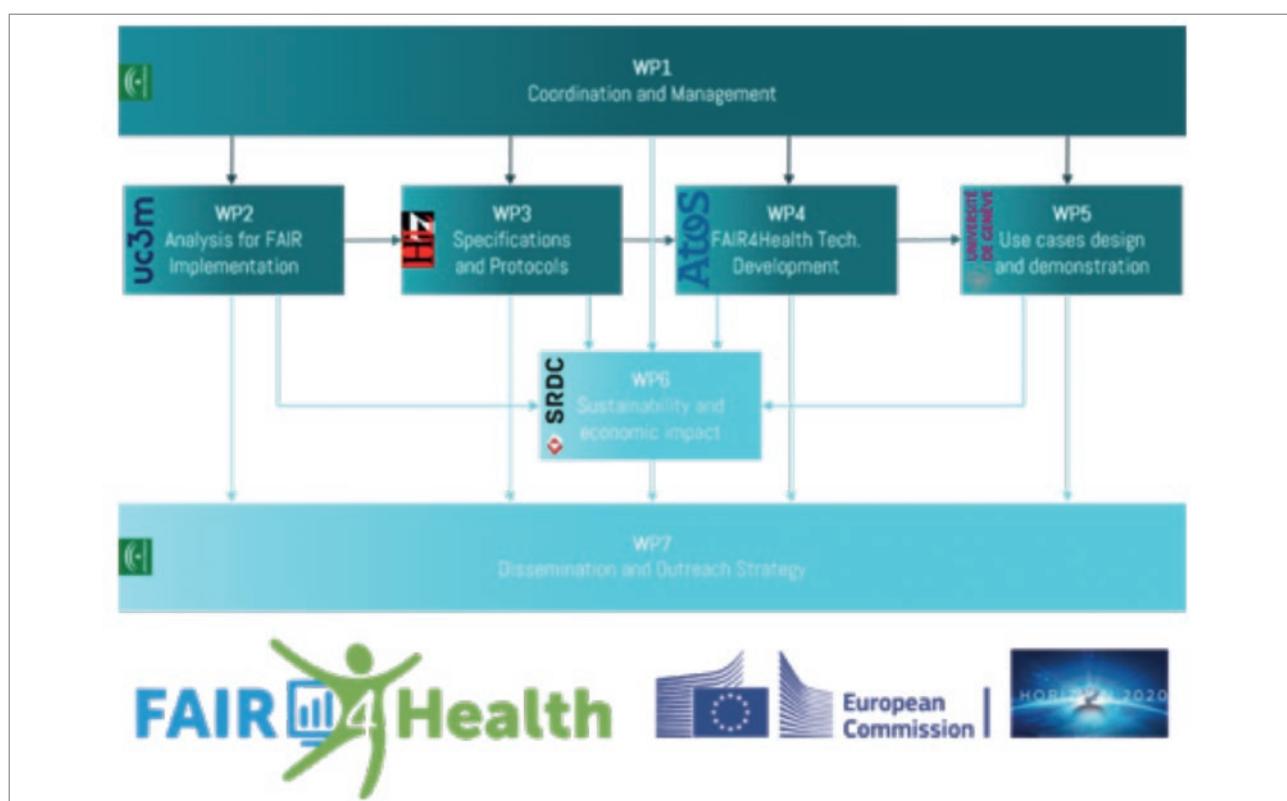
FAIR4Health technology will support the development of an open community of health research institutions in synergy with related international initiatives and projects and based on trust building and shared benefit. Potential community members will be attracted by means of the engagement and outreach strategy, and trained on the FAIR guiding principles to raise awareness about the inherent benefits that foster this strategy may have.

## Acknowledgements

FAIR4Health has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 824666.

## References

- [1] For the full list of partners, please refer to the following link: <https://www.fair4health.eu/en/partners>
- [2] Data FAIRport Initiative - [researchobject.org/initiative/data-fairport-initiative/](http://researchobject.org/initiative/data-fairport-initiative/)



# SurPass-IPS: Delivering on the social value of health data for Childhood Cancer Survivors

The electronic European Survivorship Passport (SurPass)<sup>1</sup> offers a multi-language clinical history and treatment summary along with personalized guideline-based recommendations for follow-up and screening for Childhood Cancer Survivors (CCS) to monitor, prevent or early diagnose late effects. SurPass has been developed by oncologists of the PanCare<sup>4</sup> and SIOPE<sup>3</sup> networks, supported by IT experts from CINECA<sup>6</sup>, and initially consisted of a simple web-based document template to be given to each survivor. It includes information about the original cancer and treatment received along with personalized follow-up and screening recommendations, thanks to built-in algorithms that link treatment exposure to risk factors defined by internationally approved guidelines.



After successful pilots, the web-based SurPass is used in Italian centers of pediatric hematology/oncology. Austria, Belgium, Croatia, Germany, Lithuania, Hungary, Portugal as well as Catalonia, Andalusia, and other Spanish regions are considering SurPass implementation. SurPass is essential for safe follow-up diagnosis and treatment in emergency or unplanned care of almost half a million Europeans CCS, at least 60% of which are facing a high risk of adverse health outcomes many years after treatment completion.

SurPass<sup>5</sup> is a safety and empowerment tool contributing to CCS harmonized follow-up across Europe and globally.

SurPass already uses 168 variables many of which are using internationally approved nomenclature including a new one for radiotherapy fields developed specifically for the project.

The HL7 FHIR International Patient Summary (HL7 IPS)<sup>2</sup> is an international patient summary standard for sustaining care-continuity for patients and



Catherine Chronaki, HL7 Foundation



Giorgio Cangioli, HL7 Foundation



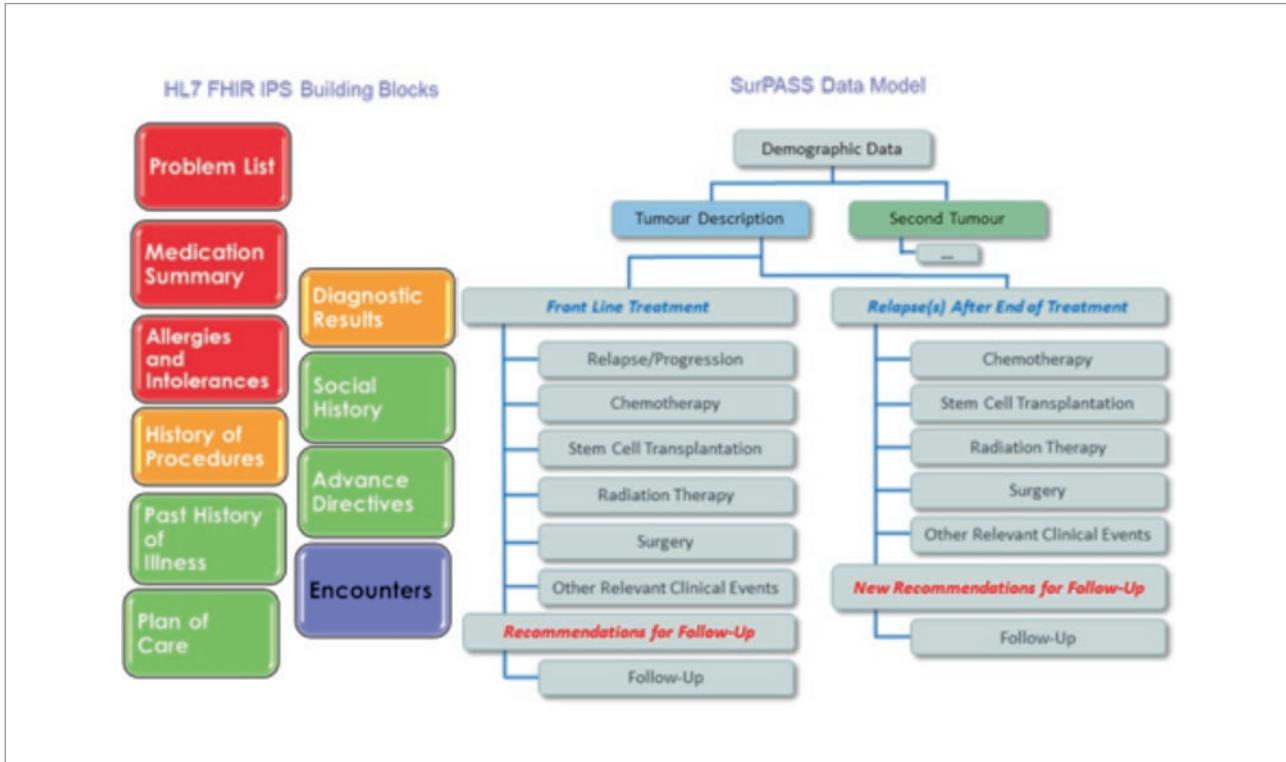
Chiara Dellacasa, Cineca

and Riccardo Haupt,  
Giannina Gaslini Institute, Italy  
PanCare,  
The Nederlands, and SIOPE, Belgium

coordination of healthcare across health systems. The HL7 IPS dataset is a robust well-defined minimal and non-exhaustive set of data elements to support both unplanned and planned care. With HL7 IPS, individuals can receive, and health professionals can provide, coordinated health and care across organizational, regional or national borders. HL7 IPS data can be assembled from one or more sources, including Electronic Health Records and information systems such as registries or perhaps in the future, be accessed through the eHealth Digital Services Infrastructure of the Connected Europe Facility in Europe.

The availability of a SurPass-IPS, a specialized HL7 IPS for Childhood Cancer Survivors, would therefore make interoperability easy and empower childhood cancer survivors to be partners in managing their health data. The HL7 IPS standard would accelerate the implementation of SurPass on mobile apps and enable SurPass-IPS connectivity of provider systems and third-party apps with less time and effort. SurPass-IPS would also advance interoperability and may prevent adverse events where possible by indicating allergies or prescribed medications for preexisting condition

SurPass-IPS is an innovative idea attesting to the social value of health data standards. Including a structured care plan, SurPass-IPS can advance



*Figure 1: SurPass Data Model next to the relevant HL7 FHIR IPS Building Blocks (red are mandatory, Green optional, while encounter was developed by the Trillium II project).*

patient empowerment and mediate patient co-operation with their health team. With sufficient commitment on the European level, this solution should increase the capacity to respond more effectively to the needs of Childhood Cancer Survivors.

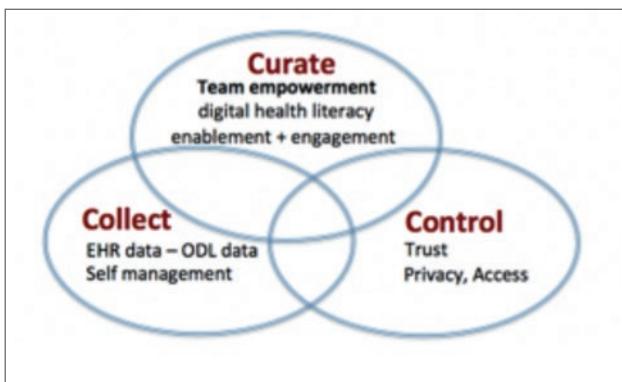
### For more information:

- [1] R. Haupt, et al. The survivorship passport for childhood cancer survivors. Eur J Cancer, 102 (2018) 69-81
- [2] HL7 FHIR IPS, <http://hl7.org/fhir/uv/ips/index.html>
- [3] SIOPE, The European Society of Paediatric Oncologists, <https://www.siope.eu/>
- [4] PanCare, PanEuropean Network for Care of Survivors after Paediatric and Adolescent Cancer, <https://www.pancare.eu/en/>
- [5] Survivor Passport <http://www.survivorshippassport.org>
- [6] CINECA <https://www.cineca.it/it/news/survivorship-passport-oncologia-pediatrica>

# Citizen and Health Data – adding opportunities for personalization



In a report from the working group "Citizen and Health Data", of the European Commission eHealth stakeholder group we presented this vision: "every European citizen should be able to collect, curate, and control relevant health information from multiple sources." The motivation is that enabling access to active use of accumulated health information supported by novel functionality and interoperability standards comes with tremendous potential to accelerate health care transformation and personalize care across Europe.



Realizing this vision can enable all citizens, able and willing, to be active, engage, and take charge in their own personal health information management, mindful of privacy considerations, capacities, choices, and contexts. Citizens can make profound difference if while contributing personal observations during treatment, use information to augment personal wellness and help out to maintain information integrity.

This vision comes with a host of challenges, including:

- a) Access, Accountability, Privacy and Trust; get access to good Health Data in digital form!
- b) Digital Health literacy; capacity to interpret, comprehend, make sense of health data
- c) Empowerment and engagement mindful of personal preferences, capacities, and abilities.
- d) Team-empowerment, cultivating citizen centered apomediation<sup>1</sup>, supported by comprehensive, relevant views of health record data and personal health data.

Anne Moen, professor, University of Oslo and past President, European Federation for Medical Informatics (EFMI)



Relevance and accuracy of data, acknowledging that a person usually knows about themselves, can build on "let patients to help"<sup>2</sup> initiatives. This will actually allow citizens participate, collect and complement without compromise of completeness, correctness, and comprehensiveness the health information in the original source. Expanding this in two directions will help personalize and collect for use the health providers' accumulated narrative of a person's health data, and the collection or inclusion of automatic (IoT-based) or purpose specific everyday observations, e.g., Observations in Daily Living (ODL), Patient Reported Outcome Measures (PROM), and Patient Generated Health Data (PGHD).

In addition to collection of personal health data, to realize this vision the citizens need new tools with functionalities to curate collected health data. Curated personal health data should stimulate comprehension and complementation to:

- a) receive, integrate, understand, compute, use digital health data to promote and preserve personal health and wellness based on current data
- b) align, correct and update all collected personal health information
- c) support personal, informed choices about health and wellness concerns on a regular basis
- d) support sense making and selection/ combinations (AI-based) to cultivate awareness, comprehension and visualizations for personal and team empowerment,
- e) engage in personal treatment, differentiate between possible choices, mindful of abilities, capacities and contexts, as well as privacy/trust preferences.

Curated health information allows the team – patient, families/significant others and healthcare professional, - to take advantage of and utilize digital solutions to co-create for care and wellness.

Lastly, citizens need appropriate solutions and tools to collect all relevant digitally stored information about themselves – including health information. The General Data Protection Regulation (GDPR)<sup>3</sup> ensures a high standard of personal data protection, including the principles of data protection by design and by default.

Change follows such opportunities. The vision for "Citizen and Health Data" calls for tools and services that let the citizen collect, curate and control personal health data. Navigation tools, like a Digital Health Compass<sup>4</sup>, can help navigate labyrinths of personally relevant health information; currently massive, confusing, contradicting, uneven quality, sometimes insufficient and sometimes too detailed information for personal relevance. Interoperability standards, e.g. HL7 CDA and HL7 FHIR®, can be employed for data portability, retrieval and sharing information mindful of practices and principles for information confidentiality, integrity, accessibility, honoring citizen's perspective on sensitivity and integrity of their information. Thirdly, codes of conduct could become resources to ensure quality of data. With wetted, relevant data emerging data analytics and AI may be perceived as more precise, efficient, personalized and trustworthy.

In sum, opening up the data sources, encourage curation of the data and nurturing trust can mobilize citizens to personalize and engage in active information management. The key mediator will be increasing capacities for digital health literacy and skills, and EFMI is ready to continue focused efforts to make this happen with its newest working group, „Citizens and health Data“



## Acknowledgements

This contribution builds on a report on 'Citizen and Health Data', presented by the eHealth Stakeholder Group, Work Group on Citizen and Health Data. EFMI, European Federation for Medical Informatics, was in the lead of this SubGroup. Members of the group were: I-HD (The European Institute for Innovation through Health Data), EMSA (European Medical Students Association), AGE Platform Europe, UEHP (European Union of Private Hospitals), ESC (European Society of Cardiology), COCIR (European Coordination Committee for the Radiological, Electromedical and Healthcare IT Industry), EPF (European Patients' Forum), AESGP (Association of the European Self-Medication Industry), PGEU (Pharmaceutical Group of the European Union), EHTEL (European Health Telematics Association), EFN (European Federation of Nurses), HL7 International, CED (Council of European Dentists), ESR (European Society of Radiology), PCHA (Personal Connected Health Alliance), VPHI (Virtual Physiological Human Institute), ECHA (European Connected Health Alliance), GMSA Europe. The eHealth Stakeholder Group mainly contributed to implementing the eHealth Action Plan and to the activities of the eHealth Network. The opinions and recommendations expressed are those of the SubGroups' members and do not necessarily represent the views of the European Commission.

<sup>1</sup> Eysenbach, G. (2008). *Medicine 2.0: Social Networking, Collaboration, Participation, Apomediation, and Openness*. Journal of Medical Internet Research, 10(3), e22. <http://doi.org/10.2196/jmir.1030>

<sup>2</sup> ePatient Dave - deBronkart, D., Topol, E.J. (2013) Let Patients Help! <http://www.epatientdave.com/let-patients-help/>

<sup>3</sup> <https://eugdpr.org/>

<sup>4</sup> Chronaki, C., Stegwee, R., Moen, A., (2018) In search of a digital health compass to navigate the health system. In Gundlapalli, A.V., Jaulent, M.-C., Zhao, D. (eds) MEDINFO 2017: Precision Healthcare through Informatics, Studies in Health Technology and Informatics. Vol 245:30-34 IOS Press

## Further information:

- European Federation for Medical Information: [www.efmi.org](http://www.efmi.org)
- European Commission eHealth Stakeholder Group: eHSG subGroup Citizens and Health Data report [https://ec.europa.eu/newsroom/dae/document.cfm?doc\\_id=58926](https://ec.europa.eu/newsroom/dae/document.cfm?doc_id=58926)
- Contact persons for more information: Anne Moen, anne.moen@medisin.uio.no

# RDCODE



A rare disease has a prevalence of less than five persons being affected out of 10 000 persons. 6% of the population is born with, or develops, a rare disorder over their lifetime. Around 30 million Europeans suffer from a rare disease which is life-threatening or chronically debilitating conditions. About 75% of rare diseases have a genetic origin, being either monogenic or polygenic. The lack of basic epidemiology for rare diseases across Europe contributes to a lack of recognition and hinders the development of appropriate services and policy. While about 70% of the world's health expenditures are allocated for reimbursement and resourcing using ICD-10, but only 8% of rare diseases have an ICD-10 classification. This means that rare diseases are under-reported, under-recognised and under-resourced in health care systems using ICD-10 and other coding systems. There is a need to implement a specific coding system allowing rare diseases patients to become visible in health statistics.

As an example, the Maltese rare disease population should be around 25,000 patients.

- The Malta Congenital Anomalies Register (MCAR) - yields over 70% of all its cases as rare but has lesser numbers with around 100-120 cases registered annually.
- The Malta National Cancer Registry (MNCR) - yields around 12% of incident cases matching rare disease diagnoses as registered in Orphanet. This means around 240 new cases of rare cancers annually. Treatment Abroad List of Patients (TA) - give over 60% out of all patients sent abroad who have documented rare disease (circa 350 per year.)
- Other sources of rare disease identification are: Rare diseases referred from website, Clinicians'



Catherine Chronaki



Giorgio Cangioli, HL7 Foundation



Ana Rath, Inserm, Orphanet



registers, Genetics data, Pathology Database, and Exceptional Medicine Treatment Pathway (EMTP). Last year, over 405 new cases were added and a total of 3258 persons suffering from rare diseases have been coded up to date (this represents > 13% of the estimated total Rare disease population in Malta). These are all living persons with a documented rare disease registered in the last 10 years from the 3 sources referred to with one of 550 types of diagnosis that have been documented so far.

The RDCODE project Kick-off meeting was held February 4th 2019 in Luxembourg. This project, coordinated by Orphanet (Inserm) is intended to support the implementation of a codification system specific for rare diseases based on the Orphanet nomenclature of rare diseases in four Member states (Czech Republic, Malta, Romania and Spain) and it is supported by a grant in the frame of the DG Santé Third Health Programme. RDCODE follows on the practical guidance on implementation developed in the frame of the former RD-ACTION, the European Joint Action for rare diseases 2015-2018, work that was recognised as a best practice by the European Commission Steering Group Promotion and Prevention (SPGG).

Ana Rath, coordinator of the RDCode project, in her welcome of the participants said: "A lot has been achieved since the last twenty years while RD codification is ongoing in many countries, however many use different nomenclatures. Because trans-national figures are essential, outstanding work was achieved by the RD-ACTION WP5 between 2015-2018 in order to provide guidelines to ensure that RD coding data across countries is comparable and exploitable.

She presented figures on how many RD are included in standard and commonly used medical terminologies such as:

■ ICD-10:

- 559 specific codes matching Orphanet rare disease entities (including groups of diseases) (= EXACT mappings)
- 513 inclusion terms matching Orphanet RD entities => 204 index terms matching Orphanet RD entities.

These figures show that in total: only 1276 Orphanet RD entities have an ICD-10 mention, but almost all ORPHA entries have been attributed an ICD11 code

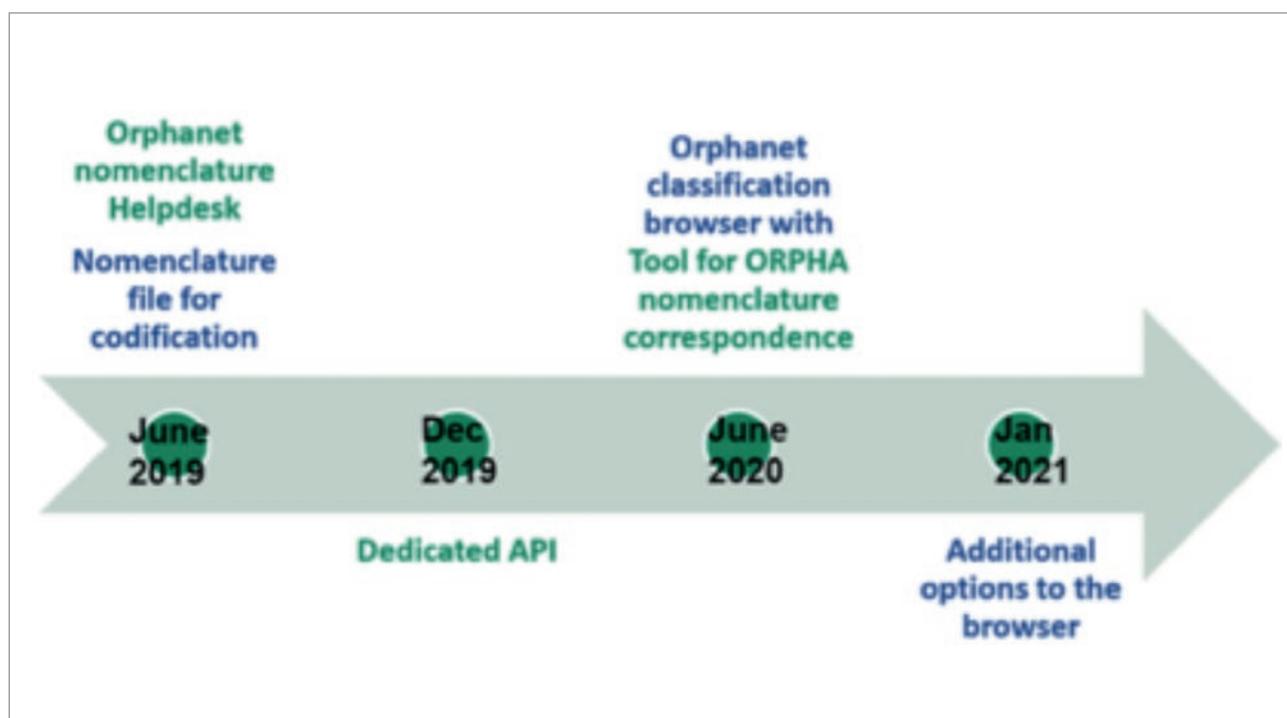
■ ICD-11:

- 60% of Orphanet RD in ICD-11-MLS - SNOMED CT (A collaboration is ongoing and a mapping file will be distributed in 2019 to licensed countries)
- 77,6% RD coverage - OMIM: => 51,65% coverage (EXACT mappings)

The update of the RD-ACTION ORPHAcodes (OCs) tool kit as well as the delivery of new Orphanet tools aimed at facilitating the practical implementation of OCs are also at the centre of the work to come. Specific activities to be carried out in the RDCode project were discussed and a roundtable was held in order to make sure that coherence and continuity with RD-ACTION is ensured and that all tools, material developed are broadly shared among stakeholders. Furthermore, the roundtable was also the occasion to share experiences with other actors, such as ERNs, EURORDIS, HL7 and inter-regional initiatives like EMRaDi aiming at building consistency in rare diseases codification across settings.

Malta, Czech Republic, Romania and Spain participate in RDCode each facing different challenges with the creation of a rare disease register. Malta will incorporate OCs in the data model in three registries and the Hospital Information System (HIS). Czech Republic will incorporate of OCs into the data model of Registry & HIS (7 European Rare Disease Networks (ERNs)). Romania will incorporate OCs into the data model of HIS (3 ERNs). Spain will incorporate OCs into the data model of Registry (6 regional registries). All countries will carry out data analysis.

Several tools will be developed in RDCode. These are shown in timeline below:



## **Guidelines for coding: bridging RD-ACTION outcomes to RD-CODE**

Data should be collected in a unified way by using an agreed list of Orphacodes for statistical reporting and coding guidelines that do not interfere with national regulations (as much as possible) but standardize the data collection so that it serves the international use case

RD-Action Project has developed international guidelines for coding Rare Diseases (RD) which will be implemented and tested in RDCODE. DIMDI and Orphanet worked together to produce a list of ORPHAcodes with their corresponding ICD codes, based on the linearization performed by Orphanet and a new integrated system has been developed using all the OC and maintaining the multidimensionality and the hierarchical structure of the classification. Afterwards, different tools have been developed: one embedded into a broader informative system supporting the activities of the RD care network and another one, in a stand-alone or a web-based version, has been made accessible to testers.

RDCODE will explore the implementing partners' context for OC adoption: Differences in country size, RD framework, health information systems, languages and settings: population-based regional registries, tertiary hospitals, ERN HCP Feedback from implementing countries regarding OC adoption for RD coding. The feedback from the implemented countries will be used to refine the already existing resources, namely the "Standard procedure and guide for the coding with Orphacodes" and the "Specification and implementation manual of the Master file".

Furthermore, to tackle the undiagnosed patients' coding issue a collection of existing experiences of coding of undiagnosed or suspected RD patients will be produced considering the project participants'

experiences. This will be the basis of a Guidelines proposal on codification of suspected/undiagnosed rare diseases that will be produced and disseminated. Recommendations should be distributed widely amongst EU-projects that try to standardize semantic content and to engage in discussions on how to use these resources as best as possible over all EU initiatives and in routine coding settings.

HL7 participates as a collaborative partner in the project with the aim to align developments of the HL7 FHIR IPS with the ERNs, paving the way towards a Rare Disease Passport; and to provide guidance on how to use OCs in HL7 FHIR, and in particular in the IPS.

*Catherine Chronaki, Giorgio Cangioli HL7 Foundation  
Ana Rath, Inserm, Orphanet*

### **For more information:**

- RDCODE project:  
[www.rd-code.eu](http://www.rd-code.eu)



- RD-ACTION project,  
guidelines for coding of rare diseases.



- ORPHANET  
<https://www.orpha.net/consor/cgi-bin/index.php>



# Interoperability of Regional EHR systems in Italy: the contribution of HL7 Italy

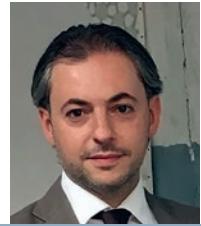


In the recent years, many efforts have been made in Italy to legislate, design and develop a nationwide interoperability platform aiming at making all the regional Electronic Health Record (EHR) systems distributed on the territory able to interact each other to exchange clinical information.

Such a platform permits a health professional who works in a region to consult all the health documents that are related to a patient he/she has in treatment of and for which he/she has access rights, even if these documents were produced by health facilities located in other regions. This way, in compliance with the regional autonomy in healthcare matter provided by the Italian Constitution, each Italian Region is implementing/adapting its own EHR system by respecting a set of national technical specifications required by specific national laws.

HL7 Italy has played a relevant role in promoting the adoption of a standardized approach to I) develop the regional IT systems in a homogenous way and II) make such systems able to interchange health information according to a shared syntactically and semantically manner.

First, it is worth noting that each regional EHR system provides a set of functions compliant to a reference functional model formalized in the document "Functional Profile – Regional Electronic Health Record (EHR) v. 1.0", that is the Italian localization of the ISO/HL7 10781 EHR-System Functional Model, Release 2.0 standard. This document, approved as DSTU in 2016, is the result of a working group coordinated by HL7 Italy and including a wide number of Italian Regions, as well as three national level organizations Invitalia, CNR-ICAR and CISIS.



Mario Ciampi,  
Institute for High Performance Computing  
and Networking of the National Research  
Council of Italy (CNR-ICAR), HL7 Italy



In accordance with a collaboration between HL7 Italy and the Agency for Digital Italy (AgID) of the Italian Presidency of the Council of Ministers, the important contribution of HL7 Italy in the last year was mainly focalized to support the process of formalizing how to represent the health content in HL7 CDA R2 documents. In more detail, the Implementation Guides (CDA2 IGs) for several types of documents have been published or are now in a ballot phase. The types of documents have been identified taking into account the ones considered strategic to the interoperability of the regional EHRs from the Technical Table coordinated by AgID and the Ministry of Health in which the representatives of Regions, Ministry of Economy and Finance, CNR and CISIS were actively involved. Specifically, the Table has constituted 9 interregional thematic groups for the definition of the information contents and the HL7 CDA R2 specifications.

From April to September 2018, five CDA2 IGs have been issued:

- The specifications to represent and code the laboratory exams are provided in the Laboratory Medicine Report CDA2 IG v. 1.2, whose first version was a result of a fruitful collaboration between HL7 Italy and IHE Italy;
- the Radiology Report CDA2 IG v. 1.0 permits to guarantee a homogeneous representation of the results of all the investigations relating to the radiological specialty;
- the specifications for representing the summaries of the results of the investigations carried out in an emergency room are described in the First Aid Report CDA IG v. 1.0;
- the modalities to formalize the data regarding a patient after a hospitalization phase are illustrated in the Hospital Discharge Letter CDA2 IG v. 1.1.1;
- the CDA2 IG for the Exemption Document v. 1.0 permits to represent the types of exemptions of a patient, as, depending on certain clinical, economic or social conditions, some medical services are provided by the National Health Service free of charge or upon payment of a ticket.

Further four CDA2 IGs are currently in a ballot phase. Three of such specifications formalize how to structure and code the data contained in pharmaceutical prescriptions, specialty prescriptions and outpatient specialty reports. The forth one is a revision of the Patient Summary CDA2 IG.

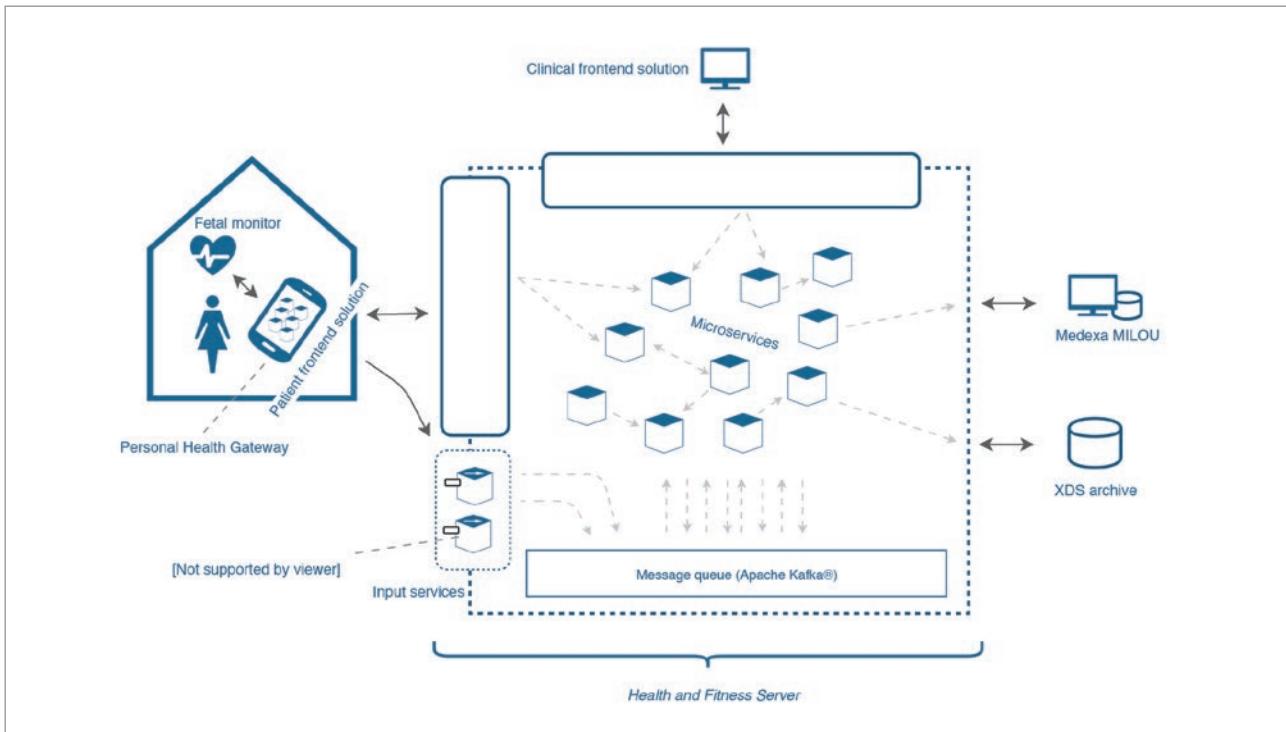
After the successful HL7 Italy event of 2018 entitled “2nd Workshop on standard and services in support of the EHR”, where a lively discussion was taken by several institutional organizations, the work done so far and the next steps to be taken will be the subject of the 3rd Workshop that will be organized in the next May 2019. This workshop will be focused on the reuse of the regional EHR data for governance purposes.

*Mario Ciampi,  
Institute for High Performance Computing and  
Networking of the National Research Council of Italy  
(CNR-ICAR), HL7 Italy*

#### **For more information:**

- Institute for High Performance Computing and Networking of the National Research Council of Italy (CNR-ICAR, <https://www.icar.cnr.it/en/persone/ciampi/>)

# Success with telemedicine for pregnant women with complicated pregnancies



A recently completed project in Denmark within telemedicine has shown that remote monitoring of pregnant women with complicated pregnancies makes a big difference. The number of hospital admissions is reduced, the women feel more secure and often they do not have to attend follow-up appointments at the hospital.

Already in 2010, Skejby Hospital in Central Denmark Region wanted to analyse if they could do something for pregnant women who were predisposed to e.g. premature rupture of membranes or pregnancy toxæmia. This category of pregnant women often go for checks and are to a much greater extent than other pregnant women admitted to hospital. Skejby Hospital therefore wanted to investigate whether it was possible to make the process easier for the pregnant women and maybe reduce the number of admissions.

A regional pilot project under Central Denmark Region was launched, and the solution was remote home monitoring, where the women were equipped with a tablet, a sphygmomanometer as well as equipment for measuring contractions and



Jacob Andersen, HL7 Denmark



fetal heart beats. The results of the measurements were subsequently sent to relevant staff at Aarhus University Hospital, the new name for Skejby Hospital after a merger with Aarhus Hospital in 2011.

Owing to the resources and finances of the pilot project there was a need for the basic software to be simple, flexible, adjustable and possible to subsequently roll out on a larger scale. Such software did not exist, and they therefore decided to develop new software.

## **Telemedicine based on open-source modules**

Together with the Alexandra Institute, which helps to develop the software, Central Denmark Region decided - as part of the research in telemedicine - to explore the possibility of building the IT system of modules, each module being easily replaceable and transferable to other applications. The idea was also to develop the system via open source, thereby enabling several parties, including other municipalities, to help develop and finance the software.

- The fundamental concept of a "module" in this architecture is a unit of software which has a single, isolated purpose, also known as a "single responsibility". This approach offers a fine-grained reuse of modules, which can be compared to building creations out of LEGOs. On a concrete system running on a server, each module will be a micro-service - a small service executing in an independent Docker container, communicating with other modules on an asynchronous bus. For apps on the users' own devices, such as smartphones and tablets, we have developed a similar run-time environment that will accept and orchestrate an assembly of independent modules – much like a "light" version of a micro-services architecture for tablets and smartphones.

## **Standardisation as quality assurance of open-source software**

When software is developed in many different places, control and quality assurance presents a special challenge. Therefore, it is absolutely necessary that the responsibility for ensuring uniform interpretation, correct data exchange, and integration of software should lie with one company only.

Today, the Alexandra Institute has governance and responsibility for quality assurance and process documentation. But data interchange between the systems (personal health device, smartphone, server etc.) was already settled in 2013 when Danish regions and municipalities agreed on the national "Reference Architecture for Collecting Health Data from Citizens", which in essence refers to the Continua Design Guidelines (published by the Personal Connected Health Alliance [PCHA]). Following this decision, national profiles were developed for the three central CDA document types: PHMR (measurements), QFDD/SFDD (questionnaires), and QRD (questionnaire responses). Furthermore, a national XDS-based infrastructure was established to collect, store, and exchange these CDA documents.

- Data interchange between individual modules on the same system requires the same level of attention; and for this purpose, HL7 FHIR was chosen as the appropriate foundation. Currently, a profile of all the main resources needed for this application is in place, based on FHIR R4. Observations and devices are modelled according to the recently developed implementation guide for FHIR R4 based communication of Personal Health Device [PHD] observations, which was on the Jan 2019 HL7 ballot.

## **Generic modules of great value to the business model**

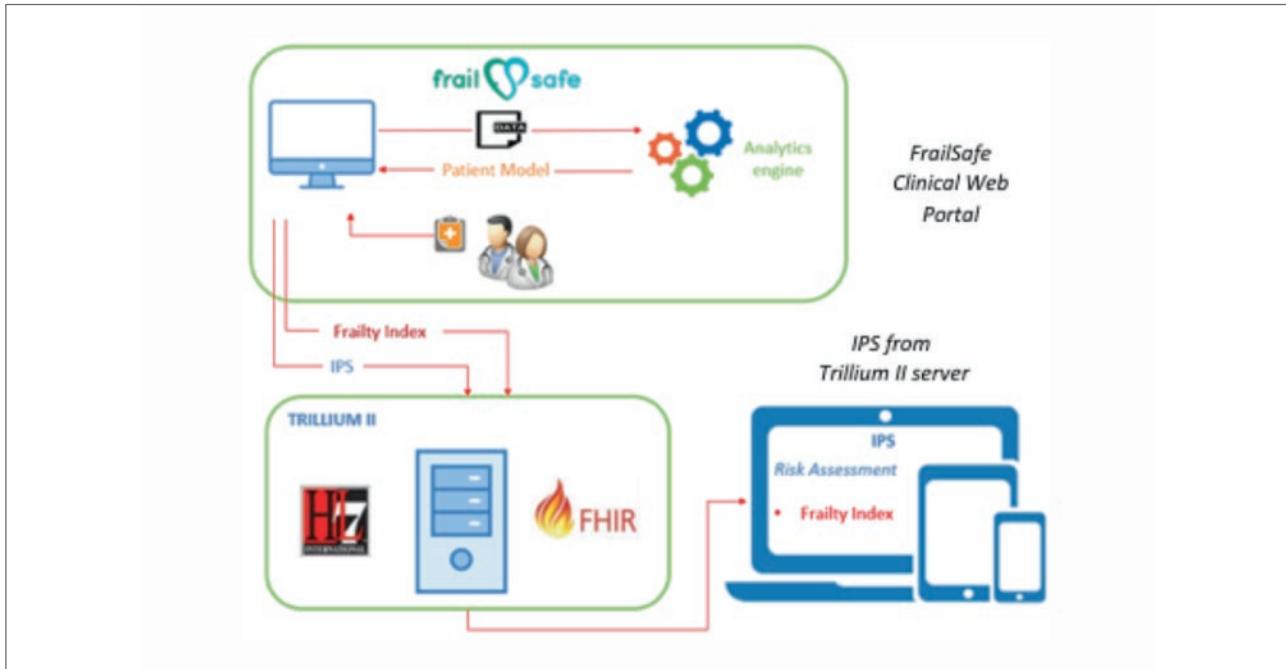
The open-source business model is not very well defined, and therefore it has been one of the objectives to find a feasible business model, and an outline of the model is now in place. In turn the business case of offering telemedicine treatment to pregnant women has proven to be working, and with fantastic results as a fact. So now Central Denmark Region is putting the system into operation, and it will be offered to the entire country in the coming years.

The thesis is that more regions will use this IT system, also for other telemedicine solutions, because of its flexibility and facility to design the modules as needed.

- The point is that the modules will be used for all sorts of things. Many of the components are completely generic and can also be used in e.g. Australia or China. Although the modules have been developed for this project, the components can be used for other projects as well. Some of the modules manage e.g. questionnaires or gather measurements from smart home monitoring systems, which can be used in other systems, e.g. for COPD patients. Other modules could show data on the indoor climate. The modules should be seen as building blocks to be selected and combined depending on what you would like to build.

*Jacob Andersen, HL7 Denmark  
Senior Software/ICT Engineer at the Alexandra Institute*

# Patient Summaries in the FrailSafe Ecosystem



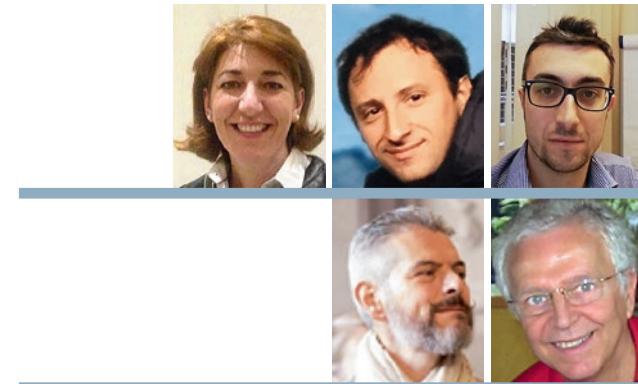
Trillium-II aims to bridge, harmonize, evaluate existing patient summary initiatives and guide emerging ones, leading the way toward one IPS standard by establishing a global community fostering the practice of digital health innovation with robust widely-used interoperability standards and joint pilots. Achieving its objective to highlight the social value of IPS standards, Trillium II collaborates with large projects such as FrailSafe to bridge IPS initiatives with validated interoperability assets and share lessons learned with standards organizations.

FrailSafe and Trillium II collaboration started during the European Innovation Partnership Active and Healthy Aging group A3 (EIP-AHA-A3) meeting, held on January 23th and 24th 2018 (Enschede, NL). The two projects have agreed to cooperate and to sign an Agreement in order to enforce the cooperation for joint activities related to digital health innovation.

FrailSafe, with 400 patients, aims, at first, to better understand frailty and identifying indicators in the transition from normal to prefrail to frail.

Particularly, FrailSafe aims to better understand frailty and its relation to co-morbidities;

- to identify quantitative and qualitative measures of frailty through advanced data mining approaches on multiparametric data and use them to predict short and long-term outcome and risk of frailty;



Cristiana Degano, PhD, Gruppo SIGLA



Matteo Toma, MS, Gruppo SIGLA

Luca Bianconi, MS, Gruppo SIGLA,  
for the FrailSafe Project

Giorgio Cangioli, HL7 Foundation

Marcello Melgara, LISPA, IT,  
for the Trillium II project

- to develop real life sensing (physical, cognitive, psychological, social) and intervention (guidelines, real-time feedback, AR serious games) platform offering physiological reserve and external challenges;
- to provide a digital patient model of frailty sensitive to several dynamic parameters, including

physiological, behavioural and contextual; this model being the key for developing and testing pharmaceutical and non-pharmaceutical interventions;

- to create “prevent-frailty” evidence-based recommendations for the elderly;
- to strengthen the motor, cognitive, and other “anti-frailty” activities through the delivery of personalised treatment programmes, monitoring alerts, guidance and education;
- and to achieve all with a safe, unobtrusive and acceptable system for the ageing population while reducing the cost of health care systems.

Even if the two projects have different aims apparently, it is evident that exists a complementarity and a common interest in the collaboration of the global community of practice in digital health innovation in order to contribute to a more sharable healthcare systems market. Since another outcome of FrailSafe project is the FrailSafe platform that can be fruitfully exploited in the healthcare context, the demonstration of its integration to and interoperability with other healthcare systems seems to be of paramount importance. From the other side, Trillium II strongly appears interested in improving the IPS in acquiring data from other healthcare platforms in order to demonstrate the possibility to share key health information, particularly related to the Risk Assessment, using HL7 standards.

Then, the joined activities have been focused on the demonstration and assessment of the interoperability between FrailSafe and Trillium II projects based on the HL7 FHIR IPS to exchange data in a common structure, focusing on testing the sharing of health information through the International Patient Summary (the patient summary standard).

The FrailSafe ecosystem provides a tool to the clinical staff, called Clinical Web Portal, to collect the data coming from the periodic visits. This platform is a web base application composed of modules, developed with the AngularJS technology, that represents the interfaces used by the users and a module, developed in NodeJS technology, that is the server side of the software with the task to interact with the data layer. For the interoperability between the FrailSafe tool and the Trillium II server, a new server module has been developed. This provides a set of APIs that allows to create, modify and delete on the server the resources, using the FHIR data models, passing the FrailSafe data.

#### **For more information:**

- Trillium II: [www.trilliumii.eu](http://www.trilliumii.eu)
- FrailSafe Project: [www.frailsafe-project.eu](http://www.frailsafe-project.eu)

# Preserved in translation

*In the 2003 movie "Lost in translation", Bill Murray portrays the challenges of collaboration and communication.*

Collaboration, information exchange and communication are vital aspects of modern health care. Few decades ago, a clinical decision was based on the decision of an experienced individual – today it is the result of multi-professional collaboration. Communication is an essential and integral part of this collaboration. In order to convey meaning, it is not sufficient that data are received unchanged – the communicating parties must also share a common understanding of the domain, concepts and terms used.

Information and Communication Technology (ICT) is often used to support communication. Standards of both technical and clinical nature are essential to enable this. While the technical standards aim at preserving the integrity of the data, the clinical oriented standards aim at preserving the meaning. Typically, the clinical concepts implemented in the communicating systems are not identical but rather carefully selected for usefulness in the specific setting. Communication standards are used as a sort of translator; The sending system converts information from its internal structure to the language of the standard – the receiving system converts the language of the standard to its internal structure. Through careful evolution of the standards as well as translation between the systems and the standard, the risk of translation errors of clinical significance may be reduced. A reduction does however not necessarily make them negligible. Sometimes, the meaning is "lost in translation".

HL7 FHIR® is an example of a standard used to define exchangeable information. Through intensive work, major involvement of users and a pragmatic view on what the most important clinical need might be, the standard has become a significant success. HL7-FHIR®-protocols are used increasingly to convey information between systems and between caregivers. Even so, the translation process still remains, and even the best communication standard cannot compensate for insufficient information models in the sending or receiving system.

CAPABLE is an R&D project supported by the Norwegian Research Council involving national as well as international participants – including HL7



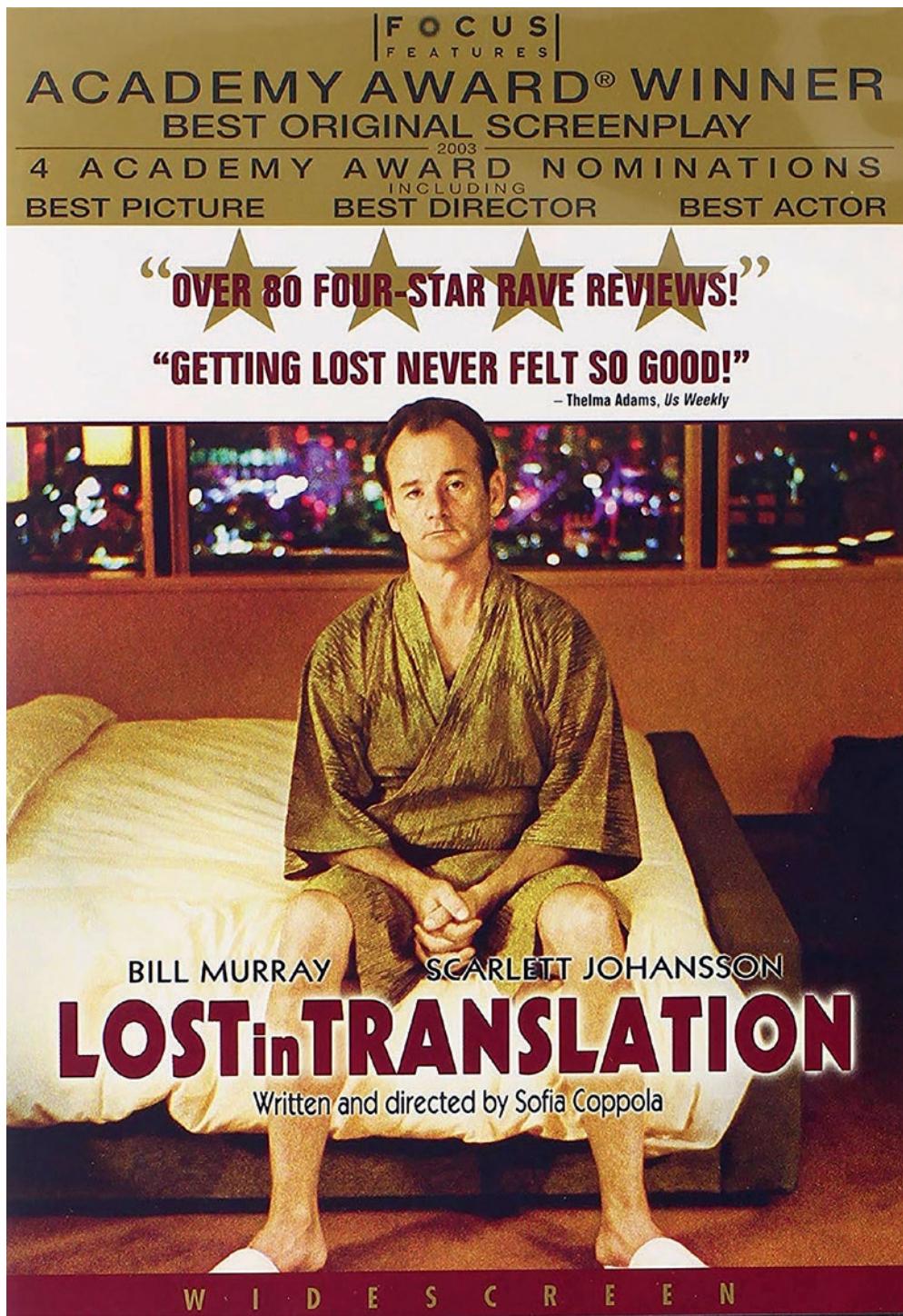
Petter Hurlen, Akershus University Hospital

Anne Moen, University of Oslo

Europe. The objective of CAPABLE is to enable citizens to actively utilize clinical and personal health information, starting with functionality to manage medication, improve nutrition, and facilitate health services coordination. Using HL7-FHIR® protocols, we are creating a personalized and universally designed digital tool to enable the user to utilize their health information in a structured, understandable, accessible and active way. The R&D challenges includes usability & accessibility, digital health literacy, interoperability, privacy, security, trust and technical infrastructure, and their reasonable trade-offs.

As one of its strategies to maintain information quality and integrity, the CAPABLE project explores how and to what extent the definitions in the various HL7-FHIR® resources and profiles can be implemented directly into the data base. Of course, the resources and profiles are made to support communication, not data storage. Using the same concepts in all parts of the communication – including in the dialogue between a server and a client, may significantly reduce any translation errors. On the other hand, standards are mostly made to represent the state of a specific process at a given point in time rather than represent the whole process. When persons may have several roles, it is the specific role in the given context that is of importance rather than the generic properties. For example, a drug may be changed in a medication treatment process, but the medication-request protocol in HL7-FHIR® describes only what drug is to be dispensed, not what drug it replaces.

CAPABLE will explore the possibilities and limitations of such use of the HL7-FHIR® standard in the area of information sharing and communication, as well as suggest additions and/or modifications to the HL7-FHIR® starting with medication, nutrition and health services coordination. The aim is that data, information and meaning are preserved in translation. We will continue to share our experiences with the international community.



#### For more information:

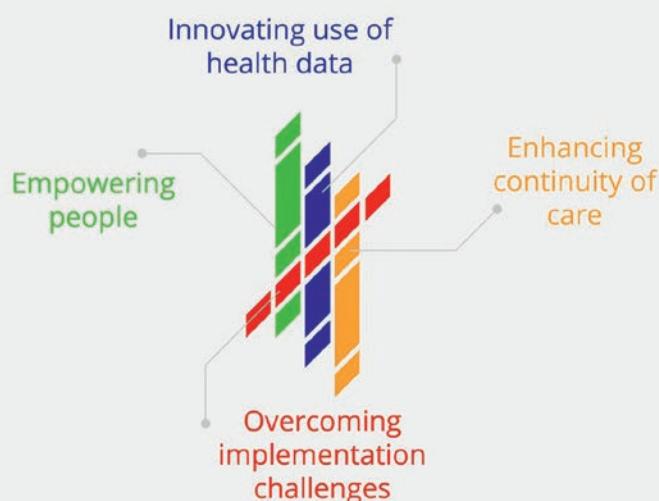
- Lost in Translation  
<https://www.imdb.com/title/tt0335266/>
- CAPABLE project:  
<https://www.med.uio.no/helsam/english/research/projects/capable/index.html>

#### Contact persons:

- Petter Hurlen, [petter@hurlen.no](mailto:petter@hurlen.no), Akershus University Hospital.
- Anne Moen, [anne.moen@medisin.uio.no](mailto:anne.moen@medisin.uio.no) (project manager), University of Oslo

# eHAction Roadmap for future eHealth Digital Services Infrastructure: Use Cases and Features

## 4 main priorities of eHAction



The eHealth Network (eHN) is a voluntary network created under Article 14 of Directive 2011/24/EU, established in order to ensure progress on eHealth and to bridge the gaps between the governance, strategy and operational levels. Responsible at a strategic level for all the eHealth policies in Europe, eHN provides a platform for Member States' competent authorities responsible for eHealth and is scientifically and technically supported by a Joint Action (JA).

eHAction is the Joint Action supporting this eHealth Network, which, in its Multiannual Work Programme 2018-2021, sets targets for exploring eHealth to facilitate the management of chronic diseases and multi-morbidity, by increasing sustainability and efficiency of health systems, and by facilitating personalized care and empowering the citizen. eHealth Digital Services Infrastructure: the road to new services and sustainability



by Christoph Gessner  
Chair HL7 Germany, eHAction Task 6.1 Leader



The current strategic Multiannual Work Programme (MWP 2018-2021) started in March 2017 and was refined by member states and the European Commission in close cooperation with the Coordinator of this Joint Action. With the four main priority areas in which the eHN activities are identified, organizational meetings were held to define and structure the next steps and, to form what the eHAction would be, as well as its impact on society.

"Member States and Countries are facing common challenges on the sustainability of health systems. Therefore, Member States are encouraged to meet eHealth objectives, at a country and regional levels, on the promotion and use of Information and Communication Technology (ICT) in health care development. These objectives may be aligned with their own national strategies, implementation guidelines, the European Union (EU) governance and strategic implementations."

(Henrique Martins eHAction Coordinator)

The eHAction also functions as a platform for organizational, strategic and technical cooperation between European member states and associated countries, including close collaboration with the European Commission and other EU stakeholders.

In the course of eHAction WP6 („Enhancing continuity of care“ - one of eight eHAction work packages) 29 participants from 17 European countries met on March 18th, in Brussels, for the 2nd workshop on the eHAction roadmap for future eHDSI use cases and features. The meeting was co-located with the CEN-International Patient Summary (IPS) final conference that took place on the following day, and CEN delegates from the member states were invited to join (including HL7 and IHE representatives as partners of the CEN-IPS).

The European Commission representatives and the member states' experts involved in the eHAction then debated options for a joint coordination process, and practical work items to extend the current portfolio of the eHealth Digital Service Infrastructure (eHDSI).

The discussion was structured by using the Refined eHealth European Interoperability Framework (ReEIF) to gain insight on the standards and interoperability assets already available or expectable to exchange data in current and additional information domains (patient summary, ePrescription, hospital discharge letters, imaging data, laboratory data).



#### **For more information:**

**eHAction Project:** [ehaction.eu](http://ehaction.eu)

**eACTION Newsletter:**

[http://ehaction.eu/wp-content/uploads/2019/04/eHAction\\_-Newsletter2-.pdf](http://ehaction.eu/wp-content/uploads/2019/04/eHAction_-Newsletter2-.pdf)

**Contact:**

Christof Gessner, [christof.gessner@gematik.de](mailto:christof.gessner@gematik.de)

# Enabling Integrated Care for Chronic Disease Patients with the Help of International Patient Summaries

A growing share of the population (15% in 2010) in OECD countries is over 65 and expected to reach 22% by 2030. Older age is associated with an increased accumulation of multiple chronic conditions (multi-morbidity), including a growing number of functional and cognitive impairments. Multi-morbidity creates diverse, and sometimes, contradictory needs, which challenge patients and the delivery of health services.

Managing multi-morbidity, through the current treatment methods, results in specialty silos involving multiple health and social care providers who are not effectively communicating and sharing information. As the number and complexity of health conditions increase over time and episodes of acute illness are superimposed, the type and number of care providers contributing to the care of individuals also increases. It becomes significantly more difficult to align and coordinate care across care teams and associated settings. Without secure information exchange among the key actors and a process to reconcile potentially conflicting treatment plans, it is impossible to avoid redundant and potentially harmful interventions.



On March 08, 2019, the C3-Cloud and Trillium-II Projects funded by the European Union H2020 programme have signed a memorandum of understanding to collaborate for reinforcing the integrated care architecture supported by C3-Cloud project with International Patient Summary framework fostered by the Trillium II project.



Gökçe Banu Laleci Ertürkmen  
Deputy Director, SRDC A.Ş.



The C3-Cloud Project (A Federated Collaborative Care Cure Cloud Architecture for Addressing the Needs of Multi-morbidity and Managing Poly-pharmacy), established an ICT infrastructure enabling continuous coordination of patient-centred care activities by a multidisciplinary care team members. A Personalised Care Plan Development Platform allows, collaborative creation and execution of personalised care plans for multi-morbid patients with the help of Decision Support Modules for risk prediction and stratification and personalized care plan goal and activity suggestions based on clinical guidelines.



Aiming to orchestrate the care across multiple care givers and treatment sites, and automatically process patients' EHRs to be able to recommend personalized treatment goals and interventions, inevitably requires interoperability to exchange and seamlessly process medications, conditions, interventions and patient reported data including



sensor measurements. C3-Cloud has chosen to build the interoperability layer based on RESTful interfaces of the HL7 FHIR standards framework. The C3-Cloud Care Plan Management platform accesses the patient's most recent EHRs, through FHIR based interfaces implemented on top of the proprietary APIs provided by local EHR systems in the pilot sites. Yet, these interoperability adapters are custom built to support the processing of heterogeneous data sources provided by pilot sites, which is challenging.

Trillium-II (Trillium Bridge II - Reinforcing the Bridges and Scaling up EU/US Cooperation on Patient Summary), aims to bridge, harmonize, evaluate existing patient summary initiatives and guide emerging ones, leading the way toward one IPS standard by establishing a global community fostering the practice of digital health innovation with robust widely-used interoperability standards and joint pilots. Trillium II explores extended usages of the International Patient Summary (IPS) by using a HL7 FHIR representation of the IPS.

C3-Cloud and Trillium-II recognize the importance of patient summary standards and share the vision of the patient summary as a window to a patient's health information enabled by robust and widely adopted specifications. The two projects agreed to collaborate on a pilot for chronic disease management to highlight the utility of patient summaries connected to the care plan in facilitating coordinated care. As a part of the joint chronic disease management pilot, C3-Cloud interoperability framework has been extended to consume IPS represented as a FHIR bundle, and stores it to its native OnFHIR FHIR repository, to be readily processed by the care plan management framework and the clinical decision support services. In this way, it becomes much easier for C3-Cloud framework to be integrated local care sites.

The joint demonstration has been presented during the 5th European Union Module Exercise (EU MODEX-Ro) to showcase how IPS can be used in

the context of a disaster medicine and emergency response exercise for supporting the care of chronic disease patients.

*Gökçe Banu Laleci Ertürkmen  
Deputy Director, SRDC A.Ş.*

**For further information:**

- C3Cloud project and factsheet:  
<http://c3-cloud.eu/home>,  
<https://cordis.europa.eu/project/rcn/202635/factsheet/en>
- Trillium II Project and factsheet:  
[www.trillium2.eu](http://www.trillium2.eu),  
<https://cordis.europa.eu/project/rcn/206099/factsheet/en>
- Trillium II IPS Implementation guide:  
<http://www.hl7.it/fhir/build/trillium2>
- HL7 FHIR IPS Implementation guide:  
<http://hl7.org/fhir/uv/ips/2018May/index.html>
- OnFHIR, HL7 FHIR® Based Secure Data Repository,  
<https://onfhir.io/>
- EUMODEX-Romania Evaluation of IPS:  
<https://trillium2.eu/news-and-events/eu-modex-ro-civil-protection-exercise>

**Contact**

Gokce Leleci Erktumen, [gokce@srdc.com.tr](mailto:gokce@srdc.com.tr)

# HL7 FHIR IPS in a CDISC World: Expanding the Patient Summary Ecosystem

The Memorandum of Understanding between the United States Department of Health and Human Services and The European Commission, on cooperation surrounding health related Information and Communication Technologies (HHS-EC MOU), signed in December 2010, is aimed at promoting individual and community health in a global environment.

The European Union and the United States recognized Health related information and communication technology (frequently referenced as "eHealth" and "Health IT" respectively) as a rapidly developing area of high innovation potential particularly for the delivery of health services, including disease prevention and health promotion. Meanwhile, the Transatlantic Economic Council has decided to promote interoperability of eHealth/Health IT products and services, consistent proficiency recognition of the professional workforce, while helping prevent unnecessary regulatory divergences.

Key to the implementation of the MoU was enabling a robust and innovative global eHealth/Health IT ecosystem. This ecosystem would support the electronic exchange of human- and machine-readable health, clinical, medical and management information to advance the health of individuals and communities. Inter-governmental cooperation and collaboration between governments and the private sector would maintain and enhance this ecosystem through specific activities and approaches to implementing transatlantic and global interoperability. Concrete steps and activities were specified in three editions of the HHS-EU MoU roadmap and associated action plans.

The Vision of the Transatlantic eHealth/Health IT Cooperation Roadmap third revision in 2016 has been:

*To support an innovative, collaborative community of public- and private-sector entities, including suppliers of eHealth solutions, working toward the shared objective of developing, deploying, and using eHealth science and technology to empower individuals, support care, improve clinical outcomes, enhance patient safety and improve the health of populations.*



Catherine Chronaki,  
Secretary General HL7 Foundation



Rhonda Facile,  
Vice President,  
Development Opportunities, CDIS

In 2017, the Trillium II consortium comprising 20 partners from 16 countries, was selected by the European Commission to implement a number of actions included in the MoU road map.

The 2016 HHS-EU MoU Roadmap identified new activities and use cases that recognize the importance of developments such as software designed for mobile and medical devices, and empowerment of patients to use their Internal Patient Summary (IPS) data, in addition to advancing standardization with projects such as the CEN/IPS project and the HL7 CDA and HL7 FHIR IPS projects.

The agreement between HL7 and CEN in February 2016 and the HL7 SNOMED agreement on February 2019 for a free set of SNOMED terms for use in the IPS, show increasing interest in promoting the patient summary as a window to a person's health information in an IPS ecosystem supporting diverse use cases. One of the use cases included in the proposal was clinical research.

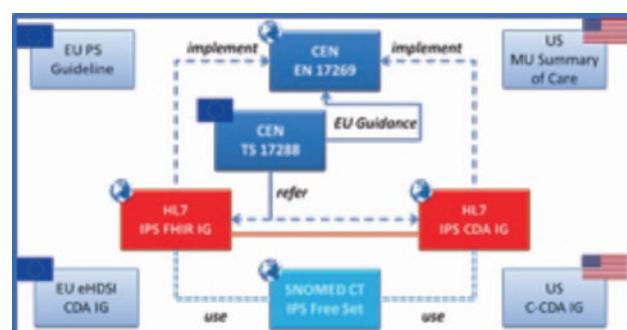


Figure 1: Four closely linked global IPS standards with EU Implementation Guidance

Having developed the HL7 FHIR IPS Implementation guide, discussions started with CDISC on the potential role of the IPS in clinical trials and in particular mapping the IPS to CDISC standards for the purpose of global regulatory submissions.

HL7 FHIR IPS and its extensions developed in the Trillium II project, support the EHRxF recommendation endorsed by the European Commission regarding the use of a core set of data items.

In the framework of the Trillium II project, CDISC and HL7 Foundation will explore ways to bridge the relevant standards starting with a sub-set of the mandatory elements of the IPS, (i.e. Problems List, Medications and Allergies. If this exploratory study succeeds, FHIR standardization will be proposed to both the HL7 and CDISC communities. This will potentially improve patient selection for clinical trials and further simplify the movement of critical patent summary information through the development process to global regulatory submissions, by building a bridge between clinical trials, health and care.

### For more information:

- CDISC: [www.cdisc.org](http://www.cdisc.org)
- HL7 FHIR IPS extensions for Trillium edition: <http://www.hl7.it/fhir/build/trillium2/site/index.html>
- <https://ec.europa.eu/digital-single-market/en/transatlantic-cooperation>
- [http://ec.europa.eu/information\\_society/newsroom/image/document/2016-30/eu\\_us\\_roadmap\\_16674.pdf](http://ec.europa.eu/information_society/newsroom/image/document/2016-30/eu_us_roadmap_16674.pdf)
- <https://www.state.gov/p/eur/rls/or/2016/260928.htm>



### About CDISC

CDISC creates clarity in clinical research by convening a global community to develop and advance data standards of the highest quality. Required by the United States Food and Drug Administration (FDA) and Japan's Pharmaceuticals and Medical Devices Agency (PMDA) and adopted by the world's leading research organizations, CDISC standards enable the accessibility, interoperability, and reusability of data. With the help of CDISC standards, the entire research community can maximize the value of data for more efficient and meaningful research that has invaluable impact on global health. CDISC is a 501(c)(3) global nonprofit charitable organization, with over 470 members, and is headquartered in Austin, Texas, with hundreds of employees, volunteers, and member organizations around the world.

*Catherine Chronaki,  
Secretary General HL7 Foundation*

*Rhonda Facile,  
Vice President, Development Opportunities, CDISC*

# Digital Health Systems of the Future



Digital health plays a significant role in achieving key public health priorities put forth by the European health policy framework, Health 2020, which advocates for strong intersectoral mechanisms to address risk factors and determinants of health in order to reduce health inequalities and significantly improve the health and well-being of populations. The United Nations 2030 Agenda for Sustainable Development incorporates and extends Health 2020 by strengthening the capacities of Member States to achieve better, more equitable, sustainable health and well-being for all, throughout the life course.

To support Member States in the digitalization of their health systems, the World Health Organization Regional Office for Europe, together with the Norwegian Centre for e-Health Research, welcomed over 350 guests for the Symposium on the Future of Digital Health Systems in the European Region at the UN City in Copenhagen on 6-8 February 2019. Stakeholders from international organizations, academia, private sector, foundations, key partners, thought leaders and Member State representatives joined together to discuss evidence and experiences in adopting digital health to reduce inequalities and improve the health and well-being of populations.

The Symposium, opened by Dr. Hans Kluge, Director for Health Systems and Public Health at the Regional Office for Europe, provided a collaborative environment for knowledge-sharing, preparing for the future and accelerating action.



Clayton Hamilton and Carrie Peterson, PhD

Digitalization of Health Systems,  
Division of Health Systems and Public Health  
WHO Regional Office for Europe,  
Copenhagen, Denmark

Over 30 plenary and parallel sessions were hosted as part of a programme that centered around key themes of governance and leadership for the future of digital health, creating national digital health success, next generation health systems, and working together to create health services of the future. Countries also provided input to the development of a regional roadmap for the digitalization of health systems, with the most relevant challenges and enablers addressed through a unique public health lens.

The session on Artificial Intelligence and machine learning in health systems and health service delivery gave insights on leveraging public-private partnerships to supplement current limitations of policies. The need for a more nuanced discussion on the multi-faceted nature of health challenges was highlighted to aid developers in building fit-for-purpose tools. Ethical frameworks for AI in health



were also stated as essential for establishing and maintaining trust, as was evidence-based standards to underpin “digital assurance” by populations in the appropriate use of their personal data.

Unsurprisingly, standards and interoperability were discussed during multiple sessions during the Symposium. One interesting example illustrated the case for developing evidence standards for digital health that mandate evaluation methods to be embedded within the standards themselves. However, despite the continued recognition of the need for standards and the growing “public investment case” for developing national interoperability frameworks for digital health, it was acknowledged that without a shared strategic and political understanding of what interoperability is and how it impacts the delivery of safe and affordable health care, creating a shared, efficient and flexible health ecosystem would likely prove difficult. In shaping this debate, the need to engage physicians and other healthcare professionals was emphasized as their voice was considered to be frequently absent from policy-level discussions on interoperability, despite their role as managers of integrated care processes.

By the closing of the Symposium, several key messages had emerged:

Digitalization will continue to challenge our understanding of how and where healthcare can be delivered and drive the transition to predictive and preventative models of care.

Digitalization of health systems is not simply a notion of “continuing what we’re doing now, faster and more efficiently” but is:

- Putting the individual at the centre of their own health and well-being;
- Addressing how the rights and consent of the individual can be respected and acted upon, and;
- Harnessing the value of data for health.

Digital health is centrally important to achieving universal health coverage with more efficient and effective modes of providing quality and equitable access to health for all. However, innovating towards a future enabled by digital health requires concretely linking investments for digital health to the achievement of public health objectives.

The conference website, containing video of the sessions, speaker profiles, the full agenda and a number of fact sheets, along with other resources, can be found at: <https://ehealthresearch.no/WHOisdigital>

*Clayton Hamilton and Carrie Peterson, PhD*

**For further information contact Clayton Hamilton by e-mail:**

hamiltonc@who.int  
#HealthForAll #DigitalHealth

# Digital Transformation of the Healthcare and Social Welfare Services in Finland

Finland is leading in Europe the electronic data management of health and wellbeing. Kanta services, the Finnish national repository for electronic health information established in 2007, brings concrete benefits for citizens, pharmacies and the social welfare and healthcare sector.

The current principal Kanta services include My Kanta Pages (since May 2010), Prescription Centre (ePC; May 2010), Pharmaceutical Database (May 2010), Patient Data Repository (PDR) and Patient Data Management Service (November 2013), Kelain (September 2016), and Client Data Archive for Social Welfare Services (CDA; May 2018) and Kanta Personal Health Record (Kanta PHR; May 2018).



Vesa Jormanainen  
M.D., M.Sc., Specialist in Health Care,  
Health and Social Systems Research,  
National Institute for Health and Welfare  
(THL)

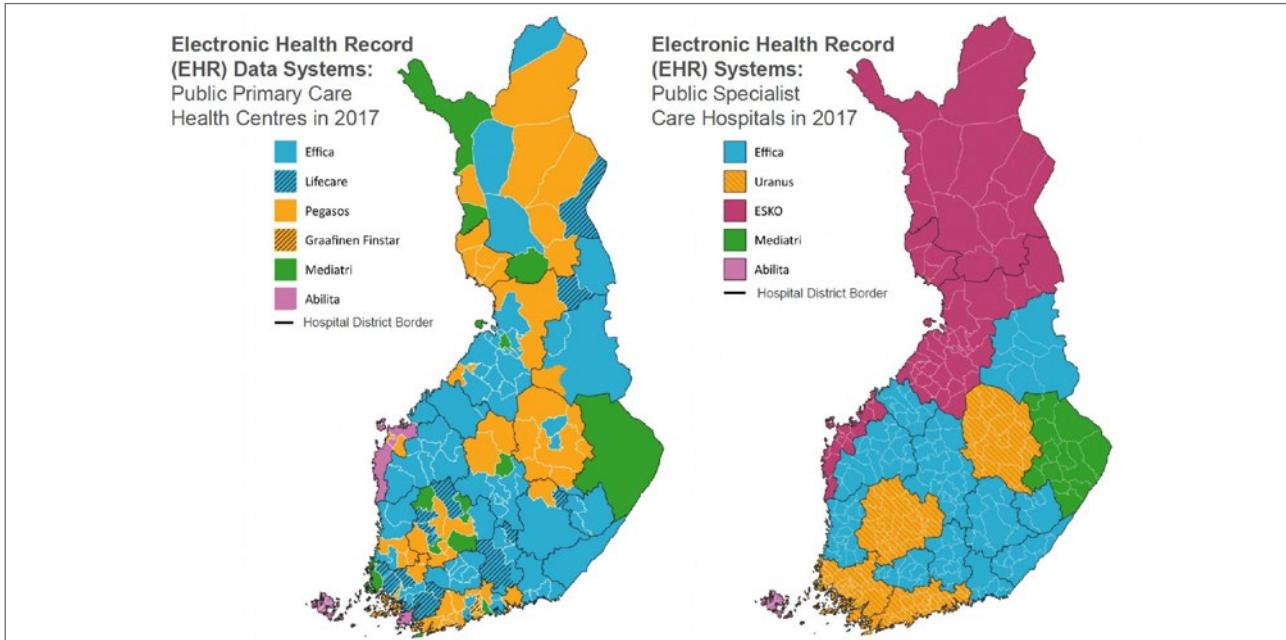


## Kanta Client Test Service

Kanta Client Test Service and Certification is offered to manufacturers of patient data and pharmacy data systems, as well as for health care organizations and pharmacies acting as their client testers. Data system manufacturers test the implementation of their systems against different Kanta services (ePC, PDR, CDA, other) before certification and for subsequent product development.

Certification is a process for verifying that information systems meet the key requirements. Certification applies to information systems related

to the Kanta services and to Kanta transmission services. As part of certification, joint testing is carried out with Kela's Kanta services and an information security audit is performed with an information security inspection body accredited by the Finnish Communications Regulatory Authority. After accepted certification, a system or transmission service receives a mandatory conformity certificate for systems joining the Kanta services. At present, 21 systems have passed joint testing for ePC, 20 systems for PDR and 3 systems for CDA. In addition, two systems have passed joint testing for archiving imaging data.



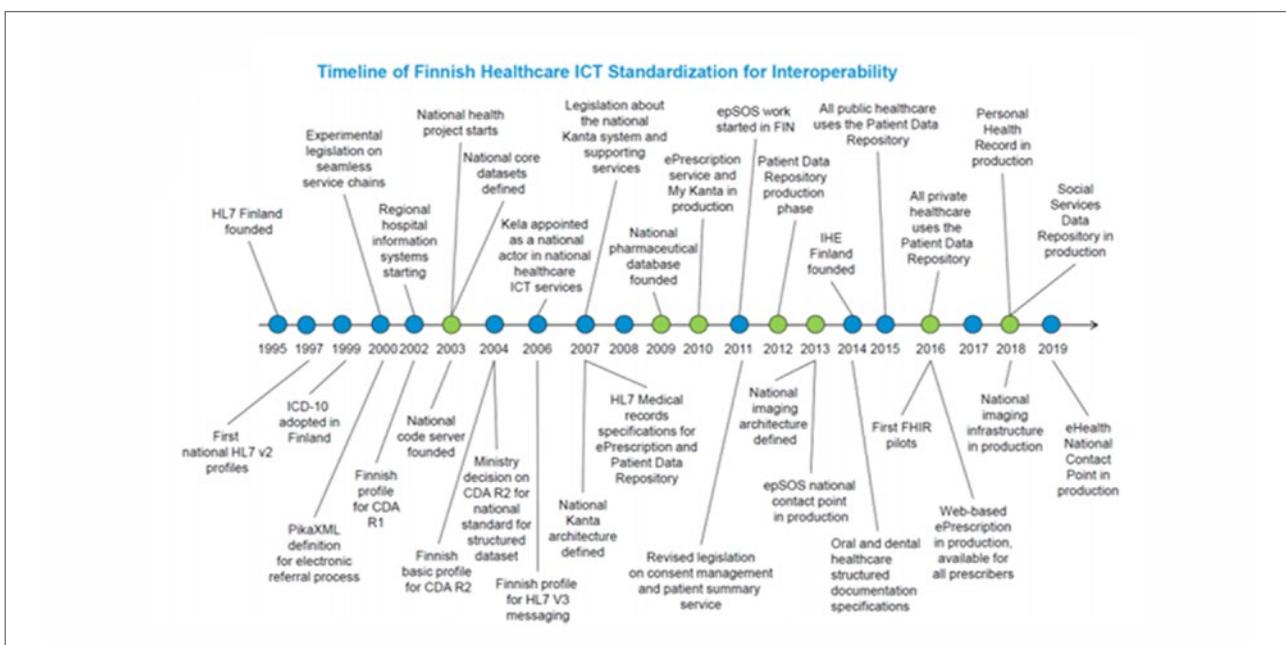
## Finish road to interoperability in health and social care

The Finnish road to interoperability has been systematic and cautious driven by long-term commitment to innovation.

### National Code Service

The National Code Service ensures the quality of the data structures used nationally in social welfare services and healthcare and to take responsibility of their development and maintenance by the

National Institute of Health and Welfare (THL). The data structures include code sets, classifications, form structures, texts, register data as well as vocabularies and terminologies related to them. The standardized data structures required by the electronic client data systems in social welfare services and healthcare as well as the central code sets of the statistical and register data collection are all published on the National Code Server. The code sets are available on the Code Server free of charge. Earlier in this year 2019, Finland joined SNOMED.



## My KanTa Pages

My KanTa Pages established in 2010 is an online service where citizens can browse their own information recorded in the ePC and the PDR regardless of whether they have used public or private healthcare services.

## Indicators

A set of indicators for prospective, longitudinal monthly follow-up are collected from the various Kanta services in Kela and sent to THL usually within a working week after end of a month. THL checks indicator data and creates charts and tables for timely reporting.

## Logins to My Kanta Pages and Number of Visitors by Month in 2010–2019

Kanta



## ePrescriptions

The Prescription Centre was launched in May 2010 and the online prescription renewals were entered in November 2015. The web portal for Electronic Prescription by health professionals was launched in September 2016. Electronic prescribing became

mandatory since January 2017, and currently some 99% of the prescription are electronic. In October 20018, 24% of all prescription renewal requests were electronic and sent via My Kanta Pages to healthcare compared to 21% in 2017.

## Electronic Prescription (eP) Renewals: Number of Renewal Requests to Healthcare via My Kanta Pages in 2015–2019

Kanta



## Cross-border Prescription Exchange between Finland and Estonia Started in 2019

An electronic prescription(eP) written in Finland can now be used outside Finnish borders, with some limitations. Finland and Estonia are the first countries where this electronic service was launched in January 21, 2019. By March 31, 2019 there were 1077 dispensations at the Estonian pharmacies from the Finnish ePs, and the monthly number will likely increase extensively during the summer months.

## For more information:

- Jormanainen V. Large-scale implementation and adoption of the Finnish national Kanta services in 2010–2017: a prospective, longitudinal, indicator-based study. [https://www.researchgate.net/publication/329435092\\_Large-scale\\_implementation\\_and\\_adoption\\_of\\_the\\_Finnish\\_national\\_Kanta\\_services\\_in\\_2010-2017\\_a\\_prospective\\_longitudinal\\_indicator-based\\_study](https://www.researchgate.net/publication/329435092_Large-scale_implementation_and_adoption_of_the_Finnish_national_Kanta_services_in_2010-2017_a_prospective_longitudinal_indicator-based_study)
- Contact: Vesa Jormanainen, [vesa.jormanainen@thl.fi](mailto:vesa.jormanainen@thl.fi)

# Bridging the Gap – engaging doctors and health care professionals in eHealth

There seems to be a gap between technologists/regulators and health care professionals in eHealth. On one hand technologists and regulators seem to regard health care professionals as change aversive and non-adaptive to eHealth solutions. On the other hand, health care professionals often feel that technologists are talking more about solutions in a distant future than solving “here and now”-problems of malfunctioning and poorly designed systems. They ask: “Why are you talking about AI when my frustration is the twenty clicks needed to register a simple procedure?”

The good news is that ambivalence, not negativism, reigns on both sides of this gap. Health care professionals are enthusiastic about well-designed eHealth solutions freeing time to patient contact. And many technologists and regulators also learn that the best and most sustainable solutions come with deep user involvement in all phases.

We need to bridge the gap, find a common ground, to bring eHealth in the right direction. To do this dialogue is needed. I have led a workgroup of health care professionals and patients’ organisations under the EU eHealth Stakeholdergroup on “New Balances – unwanted effects”. From these discussions it is obvious to me that if we want to bring eHealth forward we need:

- Discussions between health care professionals and technologists. Understanding each other – what we need and what is possible.
- To see unwanted effects of eHealth not as a threat but as a goldmine for improvements
- To measure effects and base our decisions on knowledge. We need Clinical informatics and clinical informaticians.

As a GP working from 1985 I have been through all phases of IT-development in General Practice. From nothing; paper and a ball-point pen, through the first simple EHRs to our present cascade of systems improving patient care not only through the EHR but also in safe sharing of information and communication between patient and health care professionals.



Kjartan Olafsson  
specialist of Family Medicine  
– General Practitioner in Florø – Norway,  
representative of UEMO  
(the European General Practitioners Union)  
in eHealth Stakeholdergroup 2015-18



Paradoxically our enthusiasm peaked in the beginning, when achievements were modest; “How great that I now can print referrals, sick-leaves and certificates without filling in patient name, birthdate and address every time”. Stupid design and thousands of bugs made no difference, we were happy. On our journey ahead, we seem to have passed a watershed in our attitude where unhappiness is the new feeling. We became demanding customers, annoyed by bugs, dysfunctions and lack of relevant solutions. And we are all unhappy for many different reasons. As Tolstoy puts it; “Happy families are all alike; every unhappy family is unhappy in its own way.” A common denominator is a feeling of losing valuable time to care for patients. But also, annoying details and bugs. When my X-ray referral system forces me to tick a pregnancy-box for every woman regardless of age, I feel stupid. Though it is good to give women in their nineties a good laugh. And I am getting the biblical story of Sarah retold again and again. Our focus is not the hype and hope of distant IT-solutions, but a cry for easy to use and relevant solutions. And vendors who fix the small detail that becomes a problem if you meet it fifty times a day.

Poor ICT solutions are said to be a major contributor to the growing problem of physician “burnout”. Factors are: feelings of frustration and disillusion, alienation and of losing control of work flow, being taken away from the goal and purpose of their work: caring for patients. Students,

“medical scribes”, are employed to relieve the burdens of physician’s EHR registration tasks. After repeated negative experiences many of us show signs of a negative Pavlovian conditioning. We are not meeting a new system with hope but wonder in what way it will increase my burden and take me away from my patients.

So, we forget our happiness, and must regularly remind each other of the leap forward eHealth has given Healthcare and Medicine. The UEMO eHealth Policy recognises this in the first paragraph: “The general practitioners of Europe are just as dependent on well-functioning ICT as on their stethoscope.”

In our ambivalence we love eHealth and the opportunities it gives us and our patients for better care. That is why we need to be critical, demand documentation of effect and functionality and insist on relevance to our clinical practice.

We must decide on knowledge not feelings. eHealth should be no religious movement of “worshippers” fighting off the “infidels”. Going to eHealth conferences and meetings I have always wondered why almost no presentations gives you a slide showing unwanted effects? This could be a starting point. Balancing the message will build trust and bring more health care professionals on.

We are all at the same end of the rope and need to pull in the same direction for better eHealth solutions and a bright future of improved patient care.

Let’s meet and talk, throw away old prejudices and fulfill the UEMO slogan; “Happy doctors, happy patients and happy Government”.

---

*This is my personal view, I am not writing on behalf of eHSG or the EU.*

*Kjartan Olafsson, representative of UEMO*

# How to make sure your patient summary can be shared

Across Europe numerous initiatives strive to make patient data available for a variety of purposes. Cross-border access in case of unplanned or emergency care is the focal point for the European eHealth Digital Service. Continuity of care is the aim in case of transfer of a patient to another healthcare provider institution. Patient access, as a fundamental right and as a means to empower patients to take an active role in their health and care, is another reason many patient summary initiatives are undertaken nowadays. However, if every patient summary initiative creates their own specification, it will be hard to make sure that a patient summary can be shared at all. For instance, buyers and vendors of Electronic Health Record Systems have little appetite to support the European Cross-Border Patient Summary, as the volume of patients is far too low to be profitable. The brand new set of CEN and HL7 International Patient Summary (IPS) standards aim to provide a common ground for sharing patient summary data across initiatives.

Within the Trillium II project (<http://trillium2.eu>) we aim to promote sustainable governance for the IPS. To this end we interviewed fourteen patient



Robert Stegwee,  
Chair CEN TC/251



summary initiatives across Europe and the United States. The insights are presented in the form of a governance framework. This framework is established to guide individual patient summary initiatives in setting up their own governance, ensuring that linkage with related initiatives and standards is in place. The process of collaboration between initiatives and SDOs at different levels is inferred from the actions that individual initiatives bring forward. The use of this governance framework is recommended, in order to provide a solid foundation for collaboration throughout the interlinked network of initiatives, focusing on the following key areas:

**1** Clearly identifying standards and specifications that are used, included or referenced in the patient summary specification of the initiative;

**2** Creating processes to be responsive to change, by engaging the user and stakeholder community of the initiative and through participation in the communities managing the standards and specifications as mentioned in point 1;

**3** Engaging in implementation, monitoring and auditing activities, to gather real-life experience and feedback to be used in the processes mentioned in point 2. Special attention should be attributed to building on leading practices and on addressing up-front sustainability and continuity of the effort beyond the initial stages of the project or initiative;

**4** Refining governance structures over time, reflecting both a long-term and a short-term view, in flexible structures that facilitate alignment and incentivises feedback to standards bodies.

Good governance starts by supporting the work being done in real-life patient summary initiatives. The fourteen patient summary initiatives studied provide guidance and leading practices on how to engage SDOs and collaborating initiatives in the governance of patient summary specifications. The identification of shortcomings and the coordinated propagation of change requests and approved changes throughout the network of interlinked initiatives are highlighted as the core of effective governance.

This notion reinforces the reality that patient summaries are based on real data on real patients residing in various Electronic Health Record (EHR) systems. Any patient summary initiative will strive to extract that data from these systems and present them to other users using possibly different systems, whether in a local, regional, national, or cross-border setting. A coherent set of IPS standards and specifications will help to improve the quality of the patient summary and to prevent conflict in patient summary requirements across different initiatives.

In order to take full advantage of the real-life experience that European, national and local patient summary initiatives bring, we recommend a community of experts from participating SDOs, fully engaged with these initiatives, to be formed as a single point of contact for questions about and suggested changes to the IPS standards. Apart from a global IPS community, similar communities can provide guidance at a national and regional scale, with an important role for National eHealth Competence Centres (NCCs). Their involvement

can drive the adoption of consistent IPS standards from the global community all the way down to the local implementation in Electronic Health Record (EHR) systems. Consistent local implementation is crucial for the effective exchange of patient summary data, whether in a local format on a local level or in IPS format for a national or cross-border scenario, for improved data quality and ultimately patient safety.

### For further information:

- Trillium II Project Deliverable 5.2 at [www.trillium2.eu](http://www.trillium2.eu)
- CEN IPS Draft Specifications: <https://trillium2.eu/news-and-events/>
- FHIR STU3 Trillium II IPS guide: <http://www.hl7.it/fhir/build/trillium2>
- Contact: Robert Stegwee, [robert.stegwee@cgi.com](mailto:robert.stegwee@cgi.com)

# The Joint Initiative Council: International Collaboration for Digital Health Standards

It is widely accepted that the adoption of standards is a foundational element essential to effective digital health. Today's health care demands extensive sharing of information amongst clinicians, across organizations and geographies, and also with the patient, all of which would be impossible without the use of standards. With the increasing globalization of digital health comes the equally increasing need to use internationally developed standards.

International digital health standards are produced and supported by a relatively small number of international Standards Development Organizations (SDO's). In the past, these SDO's operated independently resulting in standards that often overlapped and competed for acceptance. In 2007 the Joint Initiative Council for Global Health Informatics Standardization (known as the JIC) was formed to provide a forum for dialogue and collaboration amongst an initial group of 3 of SDO's. Having grown to include 9 SDOs representing the most prominent in the industry, current membership includes ISO/TC215, HL7 International, CEN/TC251, CDISC, IHE International, DICOM, SNOMED International, GS1, and the PCH Alliance.

As stated in its Charter, the JIC is a council of equals, with each member SDO taking a turn to chair the JIC for a 2-year term. This Chair rotation is key to the JIC's stability and sustainability over time.

While the JIC undertakes a myriad of functions, the most important is as a forum for regular collaboration amongst the senior leadership of the member SDO's. "This exchange of strategies, priorities and initiatives provides assurance to the digital health industry worldwide that SDO's are committed to ongoing dialogue, and wherever possible, joint initiatives that reduce overlapping efforts and fill needed gaps", said Michael Nusbaum, who represents IHE and is the current JIC Chair. "Users of our standards, including governments, health providers and vendors, welcome this collaboration as a signal of cooperation and stability at the international level".



Michael Nusbaum  
JIC Chair

In addition, the JIC has undertaken a number of specific joint initiatives that have led to a more harmonized approach to the development of standards. Examples of JIC successes include standards for harmonized data types, functional models for electronic and personal health records, a tool that collects and resolves standards definitions and terms, a standards set and associated guidance for implementing a patient summary record, and standards for the identification of medicinal products. Currently, the JIC is also helping to coordinate cross-SDO participation in the development of international genomics standards.

While each of the member SDO's have their particular strengths and capabilities, the JIC serves as an important vehicle to foster both the spirit of collaboration as well as cross-SDO development activities, leading to a stronger and more robust international standards community that supports digital health.

**To learn more about the JIC and how it serves and adds value to the global digital health community, visit the website at [www.jointinitiativecouncil.org](http://www.jointinitiativecouncil.org)**



# Electronic Health Record Exchange Format (EHRxF)

The EHRxF Recommendation<sup>1</sup> published on February 6, 2019 sets up a framework to achieve secure, interoperable, cross-border access to, and exchange of, electronic health data in the EU. The framework consists of principles to govern EHR access and exchange, technical specifications and an update process for the EHRxF.

High standards for the protection of health data and the security of network and information systems, combined with Identification based on eIDAS<sup>2</sup> should grant citizens and health professionals secure online EHR access. Each Member State (MS) should set up a national digital health network with clinical and technical representatives of competent authorities, the national representative of the eHealth network, and representatives of supervisory authorities established under Article 51 of the EU Regulation 2016/679 for GDPR<sup>3</sup> and EU Directive 2016/1148 for network and information security<sup>4</sup>.

## EHRxF Principles

**1** Citizen centric by design: Citizens should be central to the way in which systems are designed and implemented with data protection by design and default in compliance to GDPR.

**2** Comprehensiveness and machine-readability: EHRs should be as comprehensive as possible to support health care services across the Union. Health data in the EHR should be machine-readable, structured and codified to the extend possible.

**3** Data protection and confidentiality: EHR systems should guarantee personal health data protection and confidentiality from the design stage onward. The rights to transparent information and access (GDPR Chapter III), should allow for citizens to access their EHRs.

**4** Consent or other lawful basis: Any processing of health data must be based on the explicit consent of the citizen concerned or on any other lawful basis (GDPR Article 6 and 9).

**5** Auditability: Any processing of health data should be registered and verified for auditing purposes, to keep an accurate record of EHR access or exchange.



Catherine Chronaki  
Secretary General HL7 Foundation



**6** Security: Technical and organisational measures including cybersecurity training should ensure security of EHR systems and protection against unauthorised or unlawful processing or accidental loss, destruction or damage of health data (GDPR regulation, NIS Directive).

**7** Identification and authentication: Notified national eIDs and mutual recognition under the eIDAS regulation should support citizens' cross-border identification and authentication, while assuring the origin and integrity of EHR data when exchanged across borders.

**8** Continuity of service: Continuity and availability of EHR exchange services is essential for continuity of care and should be addressed in well-defined business continuity plans.

## Technical Specifications

Member States should take measures to ensure that the following health information domains, as a baseline, are part of an EHRxF for patient summaries, eprescription/edispensation, laboratory results, medical images and reports, and hospital discharge reports (see table on the right).

## Joint Coordination Process for further elaboration of the EHRxF

Further elaboration of the EHRxF in the context of patients' rights to cross-border health care will be done by MS in collaboration with the EC as part of a joint coordination process building on the results of existing initiatives of the eHN such as the Common Semantic Strategy task force. MS will engage in discussions and cooperation at Union

Health information domains	Clinical information for cross-border exchange	Content representation for cross-border exchange
Patient Summary	Structured according to eHN Guideline for patient summaries r2 <sup>5</sup>	HL7 CDA R3 L3 and L1 (PDF/A)
ePrescription/eDispensation	Structured according to eHN guideline <sup>6</sup>	HL7 CDA R2, L3 and L1 (PDF7/A)
Laboratory results	Enable xborder exchange according to the clinical information structure used by the sender EHR, while common structures are developed and agreed	For laboratory results, medical imaging reports and hospital discharge reports HL7 CDA R2, L3 and L1 (PDF7/A)
Medical imaging and reports		For medical imaging DICOM
Hospital discharge reports		

level with relevant stakeholders to encourage, and contribute to, an iterative process of further elaborating and adopting a EHRxF.

Finally, Members States in the context of the eHN, will cooperate with the Commission and other relevant stakeholders in establishing practical implementation guidelines, sharing good practice and promoting awareness actions for citizens and healthcare providers on the benefits of EHR access and exchange across borders

### Monitor progress towards interoperability

The eHN in cooperation with the Commission will monitor progress towards interoperability on the basis of a shared roadmap revised annually, identifying common priorities, tasks, deliverables and milestones and MS will share measures taken towards adoption of EHRxF specifications and identify common priorities and synergies with national strategies to improve cross-border EHR exchange.

MS will engage with the Commission and relevant stakeholders to identify and review emerging technological and methodological innovation and identify appropriate steps to achieve progress in the long-term EHR exchange. Refinement of EHRxF should consider the possibility offered by resource driven information models (such as HL7 FHIR). Review of new approaches to interoperability specifications, such as relevant APIs and developments in digital technologies such as artificial intelligence, cloud computing, interaction technologies, high performance computing and cyber security solutions will be carried out. Evolution in other technologies such as distributed ledger technologies may have the potential to build trust amongst citizens and health care organisations provided that they comply with personal data protection rules. The above technologies will be considered with a view to supporting innovation in health care service provision, offering new possibilities to address issues such as health data provenance, and automated integrity assurance.

### In retrospect

Technical specifications selected for the EHRxF data refer at baseline to HL7 CDA. Period review and alignment of local specifications to global standards and implementation guides is of paramount importance and cooperation of HL7 and CEN has a role to play. Taking into consideration work of the ONC Standards advisory and relevant instruments around the world as well as regular meetings to exchange best practices would create a culture of interoperability driven by the soft power of sharing problems and solutions. The discussion and recommendations of Trillium II D5.2 also contribute in the area of alignment and sustainability of component specifications linked to the HL7 FHIR resources that in the future are also part of the HHS standards advisory.

*Catherine Chronaki, Secretary General HL7 Foundation*

### References

- [1] [https://ec.europa.eu/newsroom/dae/document.cfm?doc\\_id=57253](https://ec.europa.eu/newsroom/dae/document.cfm?doc_id=57253); [https://ec.europa.eu/newsroom/dae/document.cfm?doc\\_id=57254](https://ec.europa.eu/newsroom/dae/document.cfm?doc_id=57254)
- [2] <https://ec.europa.eu/futurum/en/content/eidas-regulation-regulation-eu-ndeg9102014>
- [3] <https://eur-lex.europa.eu/legal-content/EN/TXT/?uri=celex%3A32016R0679>
- [4] <https://eur-lex.europa.eu/legal-content/EN/TXT/PDF/?uri=CELEX:32016L114>
- [5] GUIDELINE on the electronic exchange of health data under Cross-Border Directive 2011/24/EU Release 2 – Patient Summary for unscheduled care [https://ec.europa.eu/health/sites/health/files/ehealth/docs/ev\\_20161121\\_c010\\_en.pdf](https://ec.europa.eu/health/sites/health/files/ehealth/docs/ev_20161121_c010_en.pdf)
- [6] GUIDELINE on the electronic exchange of health data under Cross-Border Directive 2011/24/EU Release 2 – ePrescriptions and eDispensations [https://ec.europa.eu/health/sites/health/files/ehealth/docs/ev\\_20161121\\_c0091\\_en.pdf](https://ec.europa.eu/health/sites/health/files/ehealth/docs/ev_20161121_c0091_en.pdf)

# HACKING HEALTH Athens has HL7 FHIR IPS as its central theme



*e-Health Forum and Biomimicry Greece Research & Innovation brought HACKING HEALTH in Greece with the vision to promote digital health integration for equal access and a sustainable future. The 1st HACKING HEALTH ATHENS was organised in Athens on February 8 to 10 2019. During the Hackathon participants formed teams that worked to create innovative solutions for fostering HEALTH DATA AND MOBILITY, which was the core theme of the hackathon.*

Hacking health (HH), a global movement, fosters collaborative innovation by engaging key groups of stakeholders to create solutions to healthcare challenges. The eHealth Forum is on a mission to build a community involving a broad range of stakeholders that learns by engagement with digital technology in health and medicine. Digital health requires health data that derive from different sources and are reliable. Electronic Health Records provide this information. However, the fact that health records may be very extensive or specialized, and complex to work with. Thus, the recognized need to work with a globally accepted minimum set of data, i.e. the International Patient Summary (IPS). The IPS dataset is a minimal and non-exhaustive patient summary dataset that is specialty-agnostic, condition-independent, but readily usable by clinicians primarily for the cross-border unscheduled care of a patient, but also as needed in citizen mediated and controlled settings.

The HH Athens Hackathon organizers approached universities and communities interested in the subject of digital health including citizens and health professionals & patients. During the HH weekend



Lina Nikolopoulou,  
eHealth Forum Director



hackathon, technology creators and healthcare professionals collaborated to provide human-centric solutions to front-line problems! Teams quickly formed, collaborated and tested ideas with functional prototypes – all in one weekend.

## **The Hacking Health Athens CHALLENGE:**

A Patient Summary is a standardized set of basic medical data that includes the most important clinical facts required to ensure safe and secure healthcare. This summarized version of the patient's medical data gives health professionals the essential information they need to provide care in the case of an unexpected or unscheduled medical situation (e.g. emergency or accident). Though this data is mainly intended to aid health professionals in providing unscheduled care, it can also be used to provide summary information in planned medical care (e.g. in the case of citizen movements or cross-organizational care paths). CEN supported the event with approved draft European standard 17269 'The Patient Summary for Unplanned, Cross-border Care' was also proposed. SNOMED International offered the free set of terms in advance to its announcement. HL7 International offered support on site for the HL7 FHIR IPS resources.

The Trillium-II project that builds on the strength of the EU/US MoU on collaboration in eHealth/ Health Information Technology and as recommended



by Trillium Bridge project and noted in its 2015 roadmap "Advance an International Patient Summary standard to enable people to access and share their health information for emergency or unplanned care anywhere and as needed starting with immunizations, allergies, medications, clinical problems, past operations and implants".

Challenges addressed by the participants included:

- Illustration (user experience) of the information on the IPS for different users (medical doctors, nurses, patients, institutions...)
- Expansion of IPS and enhanced utilization for different use scenarios (chronic diseases e.g. diabetes, oncology patients, rheumatoid arthritis patients, pain management, opioid use ...)
- Decision support system for health professionals (e.g. contra-indications on co-administration of drugs)
- Develop apps with IPS inside for people with specific health problems: frailty, diabetes, hypertension
- Develop apps with IPS inside for specific age groups: elderly, health conscious, children, expecting mothers, etc.

The resources provided to the teams prior to the hackathon included literature and a webinar on Trillium-II.

### **The winners: TimelsBrain & HealthBeat: Using HL7 FHIR IPS in prehospital emergencies**



### **TimelsBrain in suspected stroke**

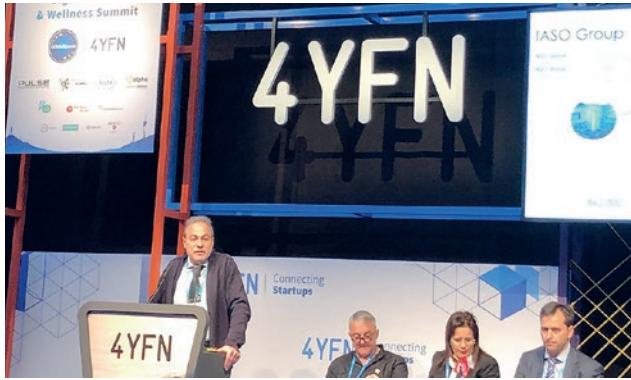
In case of a stroke, thrombolysis must take place in less than 3 hours. If the TimelsBrain platform is used, the time between the onset of the episode to the required thrombolysis is drastically reduced. The TimelsBrain platform comprises two connected applications. One is used by the rescue team in the ambulance and the other by the hospital stroke management team. Thus, the time between the first contact of the stroke patient with the healthcare professional of the ambulatory service and the thrombolysis treatment within the hospital is reduced. TimelsBrain won the first prize in Hacking Health Athens (see relevant article).

### **HealthBeat networking citizens and rescuers**

HealthBeat is a platform accessed through a mobile application, that effectively integrates health information from multiple sources, using HL7 FHIR IPS resources, for health professionals and trained volunteers to use when they need to provide assistance to an emergency call. Registered and validated users of HealthBeat can access a network of healthcare providers and helpdesks. HealthBeat allows to request services such as symptom assessment (ICPC2), medical record assessment, second medical opinion, telephone medical support 24/7, instantly detecting the location of the request. In all cases, health professionals have access to the HL7 IPS of the person requesting emergency assistance. With HealthBeat response time to an emergency call can be 3 to 4 minutes.

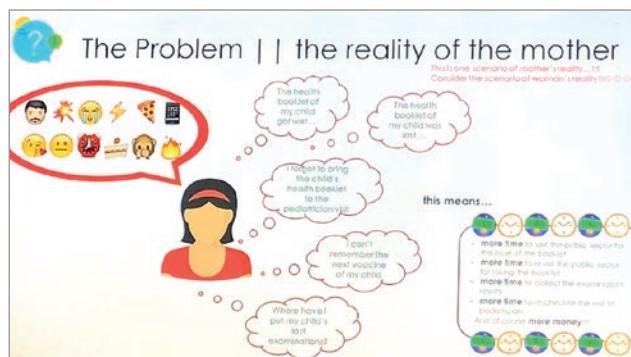
It all started from the idea to build a mobile app that in case of an emergency, helps a citizen to call for help by simply pressing a button on his/her mobile phone. Then, a whole ecosystem would be activated to rescue the person calling.

In this context, the HL7 IPS answers the question: how would the rescuer be informed about critical health information necessary to safely provide medical assistance? This is where the HL7 IPS came in the scene. HealthBeat received the 2nd prize of the HH Hackathon.



## MyBabyCare: Using HL7 IPS to support parents in child health

MyBabyCare ambition is to be an innovative, interactive, user-friendly platform for healthcare services offered to parents and their health professionals. The platform uses high security systems to ensure access only to authorised users. To healthcare providers it provides medical record since childbirth or even pregnancy, notifications or alerts about vaccination, allergies, medications, diseases, precautions, procedures, laboratory test results, etc. A mobile app for parents reminds the vaccination schedule, medical appointments, as well as useful notices. A summary medical record, extension of the HL7 FHIR IPS for children is available. The app always provides information updates on health issues by trustworthy sources. MyBabyCare received the third prize and received a lot of interest in its presentation at the 4YFN, Health and Wellness Summit of the Mobile World Congress.



## For more information

- Hacking Health Athens  
<https://hacking-health.org/athens/>
- International Patient Summary Implementation Guide,  
<http://hl7.org/fhir/uv/ips/2018Sep/index.html>
- International Patient Summary,  
[http://international-patient-summary.net/mediawiki/index.php?title=Main\\_Page](http://international-patient-summary.net/mediawiki/index.php?title=Main_Page)
- Draft European standard 17269 'The Patient Summary for Unplanned, Cross-border Care' approved,  
<http://www.ehealth-standards.eu/draft-european-standard-17269-the-patient-summary-for-unplanned-cross-border-care-approved/>
- Trillium II, <https://trillium2.eu/>
- Trillium-II Server of sample IPS resources offered by SRDC: <http://app.srdc.com.tr/fhir/stu3>
- CEN/TC 251 Health Informatics,  
<http://www.ehealth-standards.eu/>
- The International Patient Summary Standards, [http://www.ehealth-standards.eu/wp-content/uploads/2018/04/CEN-and-HL7-Patient-Summary-Standards\\_Article.pdf](http://www.ehealth-standards.eu/wp-content/uploads/2018/04/CEN-and-HL7-Patient-Summary-Standards_Article.pdf)
- International Patient Summary: Policy, deployment, competencies and standards, <https://ec.europa.eu/digital-single-market/en/news/international-patient-summary-policy-deployment-competencies-and-standards>
- 4YFN, Health and Wellness Summit, <https://www.4yfn.com/barcelona/health-summit/>
- Contact: Lina Nikolopoulou  
[nikolopoulou.lina@ehealthforum.org](mailto:nikolopoulou.lina@ehealthforum.org)



# FORTH and University of Crete win the first prize at Hacking Health in Athens!



The Institute of Computer Science of the Foundation for Research and Technology-Hellas (FORTH) and the Medical School of the University of Crete (UOC) participated in the first HACKING HEALTH HACKATHON in Athens and won the first prize, accompanied by 2,000 euros and the opportunity to participate in the Digital Transformation Programme of Roche Diagnostics Hellas.

Time Is Brain was developed to address the challenge of using the International Patient Summary (IPS) to find innovative solutions for Health Data and Mobility. Participants of the HACKATHON were asked to create innovative solutions to improve the specifications of the International Patient Summary (IPS) so that everyone can have access and share their personal health information, in order to get emergency unscheduled care, wherever needed, starting with vaccinations, allergies, drug therapy, and clinical problems.

The FORTH-UOC team developed and presented, Time Is Brain, a platform for the integrated management of emergencies focused on ischemic strokes. The Time Is Brain platform uses the HL7 FHIR IPS standard to manage emergency episodes of suspected ischemic stroke aiming at reducing the time between the first contact of the patient with the paramedics until the patient receives specialized treatment.



Dr. Angelina Kouroubali  
Team Leader, Collaborating Researcher,  
FORTH

Georgios Kaventakis  
Software Development Team Coordinator,  
FORTH

Ioannis Petrakis  
Computer Engineer, FORTH

Nikolaos Tselas  
Computer Engineer, FORTH

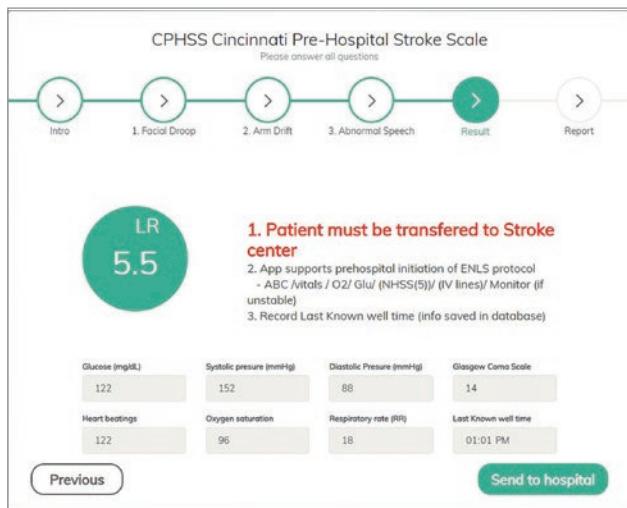
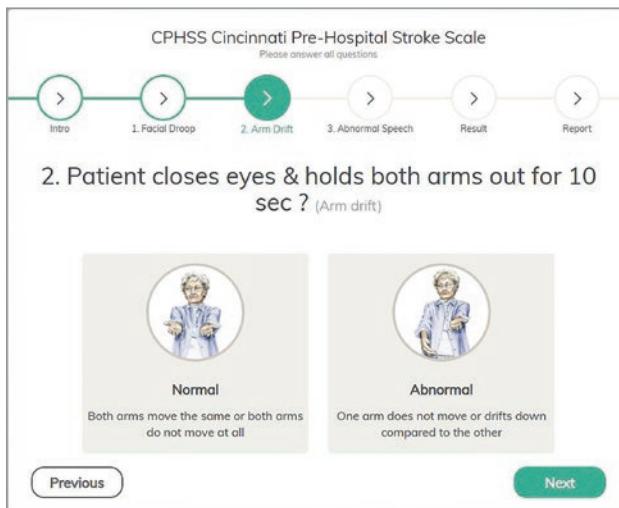
Dr. George Notas  
Assistant Professor, UOC Medical School.

The application of the rescue team guides the rescuers to decide if the episode is a probable stroke using the Cincinnati Prehospital Stroke Scale. Then, the application directs the rescuers to perform the necessary actions and measurements and to record all findings in the application. At the same time, the application provides information about the nearest hospital with a stroke management team and directs the ambulance towards it through the most rapid route.

Through the physician application, the stroke team receives the information and actions recorded by the rescuers. The application informs the stroke team about the arrival time of the ambulance to the emergency room. Smart queries retrieve important decision support information from the IPS relevant to contraindications against administering thrombolysis. When the patient arrives, the stroke team, reviews the IPS, and completes all the rest of the necessary information through checklists. All stored information and the patient consent form are printed for verifications and signatures. The Time Is Brain platform aspires

to drastically reduce the time required from the onset of the episode to the possibility of the patient receiving thrombolysis which must take place within less than 3 hours and in some cases 4-5 hours from the onset of symptoms. Delays in administering appropriate treatment results in disabilities and lower quality of life.

The IPS provides the minimal patient clinical dataset to support cross-border emergency and unplanned care. HL7 FHIR IPS was used for information retrieval in order for the healthcare professional to have all the required clinical data to decide about the specialized stroke treatment.. A public FHIR Server provided by HL7 (Public HAPI STU3 server) was used to create sample patients and their patient summaries based on the IPS standard. The Time Is Brain platform queried FHIR server's IPS for clinical data of the patient related to stroke treatment. The FHIR RESTful API used for the communication between the platform and the FHIR server. FHIR RESTful API also provided specified transactions on FHIR resources allowing flexibility on the criteria used for retrieving the



Figures 1-2: screens shots from the rescue team application

Absolute		Relative	
No major head trauma or prior stroke in the previous 3 months (IPS)	<input checked="" type="checkbox"/>	Pregnancy (IPS)	<input checked="" type="checkbox"/>
No history of previous intracranial hemorrhage (IPS)	<input checked="" type="checkbox"/>	Major surgery or major trauma in the previous 14 days (IPS)	<input checked="" type="checkbox"/>
No history of intracranial neoplasm, aneurysm, or arteriovenous malformation (IPS)	<input checked="" type="checkbox"/>	Gastrointestinal or urinary tract hemorrhage in the previous 21 days (IPS)	<input checked="" type="checkbox"/>
No intracranial or intraspinal surgery in the previous 3 months (IPS)	<input checked="" type="checkbox"/>	Myocardial infarction in the previous 3 months (IPS)	<input checked="" type="checkbox"/>
Platelet count <100,000/mm <sup>3</sup> (IPS)	<input checked="" type="checkbox"/>	Relative (Doctor input needed)	
Not receiving heparin in previous 48 h (If yes, d-dimers must be normal range) (IPS)	<input checked="" type="checkbox"/>	Stroke symptoms are not rapidly improving	<input checked="" type="checkbox"/>
Not taking an oral anticoagulant (If anticoagulant being taken, INR < 1.7 or PT > 15 s) (IPS)	<input checked="" type="checkbox"/>	Seizure with postictal residual neurological impairments	<input checked="" type="checkbox"/>
No dabigatran, apixaban, or rivaroxaban use for chronic anticoagulation for conditions such as atrial fibrillation (IPS)	<input checked="" type="checkbox"/>	<b>Print Consent Form</b>	
<b>Absolute (Doctor input needed)</b>			
Glucose <50mg/dL (CPHSS)			
No elevated blood pressure [systolic >185 mmHg and diastolic >110 mmHg] (CPHSS)			
CT does not show a nontraumatic infarction (CT)			
Symptoms of stroke are not suggestive of subarachnoid hemorrhage			
No arterial puncture at a non-compressible site or lumbar puncture in the previous 7 days			
No evidence of active bleeding or acute trauma [fracture] on examination			

Figure 3: The Time Is Brain platform queried FHIR server's IPS for the patient clinical data related to stroke treatment.



required clinical data. IPS and FHIR integration was a vital part of the Time Is Brain platform since clinical data needed for stroke treatment is very specific and require complicated search criteria.

Time Is Brain platform is a prototype. Once funding is ensured, a full commercial product will be developed and used in a pilot study to demonstrate the health and social impact of timely management of ischemic stroke emergencies. The potential markets for Time Is Brain platform are national and private healthcare and prehospital emergency care organizations and large companies such as Google, Amazon, Apple and Microsoft.

The team would like to thank all the mentors of HACHING HEALTH and especially Mr. Dimitrios Katehakis, Head of the Center for eHealth Applications and Services of FORTH and general secretary of HL7 Hellas for his valuable mentoring advice.

#### **For more information:**

- Cincinnati Prehospital Stroke Scale  
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5994852/>
- Institute of Computer Science FORTH  
<https://www.ics.forth.gr/>
- Medical School, University of Crete  
<http://en.uoc.gr/courses/faculty-sciences-health/medical-school.html>
- Contact: Angelina Kouroubali  
[kouroub@ics.forth.gr](mailto:kouroub@ics.forth.gr)

# EU MODEX Estonia: Patient Summaries in Disaster Management



The Estonian Island of Saaremaa (Greek: Θούλη Thólē, latin Thūlē), the farthest north by Pytheas from Marseille, a Greek geographer and explorer of the 4th century BC, was the location of the first European Civil Protection Module Medical Exercise of 2019 carried out on April 10-14. With support from the World Health Organization, three entry level Emergency Medical Teams (EMT) came to help a fellow European member state facing an emergency.

In EU-Modex EE, Saaremaa experienced the creation of the Kaali meteorite craters (course octahedrite was confirmed in fragments by Ivan Reinwald in 1937) which are only eighteen kilometers from Kuressaare. The fall of a meteorite caused a flash flood that devastated the small island and the coast of Estonia. Due to the limited capacity of the Kurressaare hospital and the inability of the mainland to help, the Estonian Health Board requested help from the European Civil Protection Mechanism. The Austrian, Romanian, and European EMT-1 responded to the request with 121 rescuers that were called to triage and treat more than 600 cases over 36 hours.

The Trillium II project was there to assess the value of the International Patient Summary in the management of patients. EMTs from the Austrian Red Cross, the Romanian Disaster Medicine Unit operating 24h, and for the first time a European EMT under the leadership of Estonia of British, Belgian, German, and Turkish members received patients with a mobile phone featuring an International Patient Summary (HL7 FHIR IPS). Thirty cases were earmarked for the Trillium project.



Catherine Chronaki  
Secretary General HL7 Foundation

Lucas Deimel  
Empirica, Germany

Marcos Fortes Bordas  
Tic Salut Social Foundation, Catalonia, Spain

Juan Antonio de los Cobos Molinas  
Tic Salut Social Foundation, Catalonia, Spain

If a case was assigned to Trillium II, the role player was given a mobile phone with an app developed by TicSalut, the health authority of Catalonia Spain, providing the core elements of the HL7 FHIR IPS, namely Allergies, Medications, Conditions, in addition to demographic data.





The Trillium II team on site was very agile and had to cope with many changes in the program. Catherine was making plans that changed, Marcos, the nurse in the team, aligned the patient summaries to the specific role stories, Juan Antonio, the FHIR expert, updated the patient summaries on the FHIR server just in time, and Lucas, carried out the interviews with role players and rescuers. Joan Solans was on call for remote technical support tasks from Tic Salut Social in Catalonia. The use of the App to provide the HL7 FHIR IPS connecting to FHIR Tic Salut Social server allowed us to keep up with last minute changes in the stories and role players.

The evaluation protocol was as follows. Before the case play started, the role actor is briefed one of the team players. We discussed the role and the additional data provided by the IPS on the mobile phone. We requested that the actor hands the phone to the EMT person in charge of the triage, letting him/her know that additional information was available. A member of the Trillium team shadowed the case wearing a red observer jacket and did not interfere even in cases where the role player forgot to hand in the mobile phone.

After the case (inject) was played, the team member shadowing the case asked the role player about their experience with having the mobile phone with the IPS. At breaks and after the end of the exercise rescuers that dealt with "Trillium" cases shared their thoughts about the app and the role of the patient summary. Trillium II team members shared their observations as well. To many young players having the IPS on their phone felt natural. For the rescuers, it was another source of information to consider. Rescuers liked the simplicity of the interface and would prefer if medication was linked to the problem addressed and dose information was listed. There was some concern about the authenticity/validity of the information provided in the IPS.

Over the course of three days, 15 Trillium cases were shadowed. After the end of the EU Modex EE exercise, during the SWOT analysis of the teams, I had the chance to present the perceived



strengths, weaknesses, opportunities and threats from the Trillium evaluation in EU Modex. Among the strengths listed was the lean organization of the Trillium team (IT, Health, Eval, lead) and no intervention during the role play. The well-organized role coordination center run by the disaster rescue board center of Estonia, offered elaborate stories and a base for the Trillium II to prepare the IPS cases. Having the opportunity to brief the team trainers and the exercise coordination team about Trillium II and the IPS was instrumental to receiving good feedback. The process of briefing the role players, many of medical background, and weaving the IPS into their story was a great strength of the evaluation.

The main opportunity identified was that the IPS can add value to future exercises, adding to the process of triage, health information from the person's phone and making IPS part of the training in disaster medicine. Future exercise scenarios could involve aggregating information from IPS of role players to the information system of the exercise tracking more accurately the evolving situation and resource needs. There were some weaknesses identified as well, like the need to keep up with surges in patient volumes and our inability to follow cases after midnight. Among the threats identified was the still wide use of paper, limited power supply, and lack of plug and play integration with emergency information systems where they exist.

We look forward to the next EU Modex Exercise!

*Catherine Chronaki,  
Secretary General HL7 Foundation*

#### **For more information:**

- Thule: <https://en.wikipedia.org/wiki/Thule>
- Tic Salut Social Foundation: <https://ticsalutsocial.cat/>
- EU Modex Saaremaa: <https://www.youtube.com/watch?v=CAEVtzvvlLU>
- EU Modex: <https://www.facebook.com/eumodex/>
- Trillium II project: [www.trillium2.eu](http://www.trillium2.eu)

## HL7 Affiliates in Europe

see also <http://www.hl7.org/Special/committees/international/leadership.cfm>

HL7 Austria <a href="http://www.hl7.at">http://www.hl7.at</a> Chair: Stefan Sabutsch	HL7 Germany <a href="http://www.hl7.de">http://www.hl7.de</a> Chair: Christof Geßner	HL7 Russia Chair: Sergey Shvyrev MD, PhD
HL7 Bosnia and Herzegovina Chair: Samir Dedovic	HL7 Greece <a href="http://www.hl7.org.gr">http://www.hl7.org.gr</a> Chair: Alexander Berler	HL7 Portugal Chair: Paulo Alves
HL7 Croatia <a href="http://www.hl7.hr">http://www.hl7.hr</a> Chair: Miroslav Končar	HL7 Italy <a href="http://www.hl7italia.it">http://www.hl7italia.it</a> Chair: Giorgio Cangioli	HL7 Spain <a href="http://www.hl7spain.org">http://www.hl7spain.org</a> Chair: Francisco Perez
HL7 Czech Republic <a href="http://www.hl7.cz">http://www.hl7.cz</a> Chair: Libor Seidl	HL7 The Netherlands <a href="http://www.hl7.nl">http://www.hl7.nl</a> Chair: Rob Mulders	HL7 Sweden Chair: Mikael Wintell
HL7 Denmark Chair: Sofia Stokholm	HL7 Norway <a href="http://www.hl7.no">http://www.hl7.no</a> Chair: Line Saele	HL7 Switzerland <a href="http://www.hl7.ch">http://www.hl7.ch</a> Chair: Roeland Luykx PhD
HL7 Finland <a href="http://www.hl7.fi">http://www.hl7.fi</a> Chair: Juha Mykkänen PhD	HL7 Poland <a href="http://hl7.org.pl">http://hl7.org.pl</a> Chair: Roman Radomski MD, MBA	HL7 UK <a href="http://hl7.org.uk">http://hl7.org.uk</a> Chair: Dunmail Hodkinson
HL7 France Chair: François Macary	HL7 Romania <a href="http://www.hl7romania.ro">http://www.hl7romania.ro</a> Chair: Florica Moldoveanu	HL7 Ukraine <a href="http://hl7.org.ua">http://hl7.org.ua</a> Chair: Leonid Stoyanov



### About HL7 International

Founded in 1987, Health Level Seven International ([www.HL7.org](http://www.HL7.org)) is the global authority for healthcare Information interoperability and standards with affiliates established in more than 30 countries. HL7 is a non-profit, ANSI accredited standards development organization dedicated to providing a comprehensive framework and related standards for the exchange, integration, sharing, and retrieval of electronic health information that supports clinical practice and the management, delivery and evaluation of health services. HL7's more than 2,300 members represent approximately 500 corporate members, which include more than 90 percent of the information systems vendors serving healthcare. HL7 collaborates with other standards developers and provider, payer, philanthropic and government agencies at the highest levels to ensure the development of comprehensive and reliable standards and successful interoperability efforts.

E-mail: [HQ@hl7.org](mailto:HQ@hl7.org) • Website: [www.hl7.org](http://www.hl7.org)

### HL7 Europe Listserver

If you want to be up to date regarding HL7 Europe, please subscribe to [europe@lists.hl7.org](mailto:europe@lists.hl7.org) at [hl7.org](http://hl7.org).

09 / MAY 2019

HL7 European Office  
Square de Meeûs 38/40  
1000 Brussels  
Belgium  
E-mail: [EUoffice@HL7.org](mailto:EUoffice@HL7.org)  
Website: [www.HL7.eu](http://www.HL7.eu)

Health Level Seven and HL7  
are registered trademarks of  
Health Level Seven International