

# European Patient Summary Guideline: Focus on Greece

Alexander BERLER<sup>a,1</sup> Anastassios Tagaris<sup>b</sup> and Catherine CHRONAKI<sup>c</sup>

<sup>a</sup>*Gnomon Informatics, Thessaloniki, Greece*

<sup>b</sup>*IDIKA SA, Athens, Greece*

<sup>c</sup>*HL7 Foundation, Brussels, Belgium*

**Abstract.** The European Patient Summary (PS) guideline specifies a minimal dataset of essential and important information for unplanned or emergency care initially defined in the epSOS project with aim to improve patients' safety and quality of Care. The eHealth Network of European Union (EU) Member State (MS) representatives established under Article 14 of the EU directive 2011/24 on patient rights to cross-border healthcare adopted PS guideline in November 2013 and since then the guideline has been part of MS strategic eHealth implementation plans, standardization efforts, and concrete regional, national, European and international projects. This paper reviews implementation efforts for the implementation of an operational patient summary service in Greece drawing on challenges and lessons learned for sustainable standards-based large scale eHealth deployment in Europe and abroad, as well as the reuse of best practices from international standards and integration profiles.

**Keywords.** Interoperability, large scale eHealth deployment

## 1 Introduction

The European Patient Summary (PS) guideline specifies a minimal dataset of essential and important information for unplanned or emergency care initially defined in the epSOS project with aim to improve patients' safety and quality of Care. The eHealth Network established under Article 14 of the EU directive 2011/24 on patient rights to cross-border healthcare adopted PS guideline in November 2013 and since then the guideline has been part of MS strategic eHealth implementation plans, standardization efforts, and concrete regional, national, European and international projects.

The JAseHN project assessed progress in adoption and implementation of the patient summary guideline [1] against the four layers of the European eHealth interoperability framework (eEIF) [2] namely legal, organizational, semantic (i.e. information) and technical. According to the recently released report [3] in most EU countries the Patient Summary implementation is at an early stage. Although some countries already have many of the components necessary to support implementation of the Patient Summary guideline and National Contact Point for eHealth [4], in most Member States implementation of recommended interoperable public services has not finished yet. Meanwhile development of the European Digital Services Infrastructure for eHealth (eHealthDSI) with Connected Europe Facility [5]. This paper presents patient summary

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<sup>1</sup> Corresponding Author.

design and pilot, reflecting on challenges and lessons learned toward more sustainable digital health services in Greece and cross-border.

## 2 National Patient Summary Design in Greece

The Ministry of Health in Greece as part of its Health Reform Support Program 2013 – 2015 in collaboration with WHO Europe, in the framework of Health in Action Initiative, proposed ten pillars to strengthen development, performance, and sustainability of the national health system. As part of the eHealth pillar a study recorded the status of the decentralized Electronic Patient Record systems in the public hospitals, providing suggestions for horizontal or vertical interconnectedness describing the next steps. The study proposed an interoperability architecture for deploying a national patient summary infrastructure based on the EU guidelines as set as of November 2013.

In parallel to that, the SOHealth (Smart Open Internet Services for Health <http://www.sohealth.gr/>) project was co-funded by the Greek Secretariat of Research and Technology and the European Union, to develop a national extension of established European innovation projects and networks e.g. epSOS, ANTILOPE, etc. The SOHealth consortium comprised Infolab of the Aristotle University of Thessaloniki and Gnomon Informatics SA as scientific and technical coordinator respectively, ELOT SA as the quality manager and pilot validator, as well as Pharmaxis and IDIKA SA as pilots. SOHealth focused on proposing innovative eHealth interoperability services and tools enabling cross platform, cross border and interregional healthcare scenarios based upon the reuse of international standards (HL7, IHE, etc.). Reusing the national common components (SSN registry, etc.), SOHealth created a National Contact Point (NCP) and build a patient summary reference implementation incorporating the medication related overview, the health encounter report, and proposing a patient consent framework to support patient access and engagement scenarios.

### 2.1 Patient summary related use cases

Two major categories of patient summaries were considered: a) A summary of **an encounter** which is either related to a Hospital Stay (often called a Discharge Summary) or to an GP/Specialist visit and b) an **aggregate view** across multiple care providers/encounters: summarizing the up-to-date state of a patient health and on-going treatments. The epSOS project picked the aggregate view; nevertheless some of the participating countries instead of creating aggregate reports just share the most recent discharge/encounter summary. Picking one versus the other patient summary is a hot debate. Both have pros and cons and **in fact both are needed** for different reasons:

Pros of a summary of **an encounter** are amongst others that it is *coherent and attested by a physician* (that assumes responsibility), and the fact that it is actually a *set of consistent and related information*. On the other hand, the major drawback of this kind of encounter level PS is that access to an aggregate view requires the local point of care IT system to retrieve a set of encounter PSs and perform this overview if needed by the health professional. Meanwhile, an **aggregate view** across multiple care providers/encounters has the major advantage that it can serve as an easy entry point for getting an overview of a patient's health but there are also drawbacks. Sometimes the aggregate view is imprecise for certain care situations, has no associated medical responsibility (aggregation is software driven) and it is quite challenging to handle textual data.

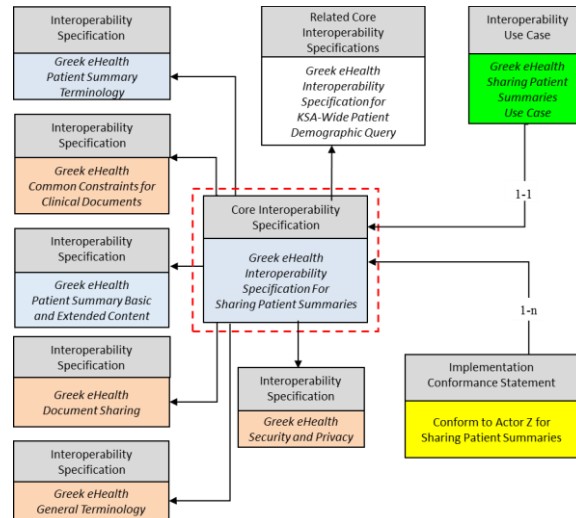


Figure 1: Core Interoperability specifications for the Patient Summary Use Cases.

The next two Use Cases focus on the transfer of patient-related information, in the form of patient summaries. As has been described by IHE, patient summaries can be classified in three categories: *collaborative*, *episodic*, and *permanent*<sup>2</sup>.

**Collaborative:** A collaborative summary serves the interests of a specific provider by “providing the most relevant information about the patient”. A referral letter from primary to secondary care may serve as an example of this type of patient summary.

**Episode:** “Episodic summaries have the primary purpose of highlighting the most relevant details of focused periods of time in a patient history. Examples include discharge summaries”. A discharge summary is a concise summary of the recent episode, and highlights the diagnosis, therapy, and recommendations for further treatment at the end of a healthcare episode. It is a transfer of information, often to the primary healthcare professional that referred the patient to the specialist. This patient summary type is the hospital discharge report.

**Permanent:** Permanent patient summaries “summarize the entirety of a patient’s medical history and therefore cover a broader range of patient problems”. A permanent patient summary is often referred to in the context of a longitudinal medical record. It summarizes the medical history of the patient, and provides information about the current health status, including the actual discharge summary. A Patient Summary is meant as a general overview of the patient’s health history and current situation. It is a concise clinical document that provides an electronic patient health data set that is applicable both for unexpected as well as planned healthcare contact. The content of the patient summary is defined, at a high level, as the non-exhaustive data set of information needed for health care coordination and continuity of care. This type of summary relates to use cases for cross border and national exchange as well as citizens access at home.

All Patient Summary types contain information such as: (a) *Demographic information* about the patient (e. g., name, birth date, gender) (b) *A medical summary* consisting of the most important clinical patient data (e. g. medical history, past surgical

<sup>2</sup>[http://wiki.ihe.net/index.php?title=PCC\\_TF-1/XDS-MS-Cross-enterprise\\_Sharing\\_of\\_Medical\\_Summaries\\_.28XDS-MS.29\\_Integration\\_Profile](http://wiki.ihe.net/index.php?title=PCC_TF-1/XDS-MS-Cross-enterprise_Sharing_of_Medical_Summaries_.28XDS-MS.29_Integration_Profile)

procedures, allergies, current medical problems, medical implants (c) *A list of the current medication*. There is much debate as to what constitutes a “current medication list”. Generally, it consists of prescription and dispensing information. Information about the patient summary itself (e. g., author, date that the patient summary was generated). The relevant specifications appear in Figure 1.

## 2.2 Interoperability Architecture

The proposed interoperability architecture (**Error! Reference source not found.**) enables all types of existing systems to participate and exchange information under one unique information model and supports different modes of data exchange. Point of care systems irrespective to technical complexity, technological model or other specificity driven by point of care variations can connect to these components. In this way, the time and implementation cost of the national eHealth strategy in Greece is reduced.

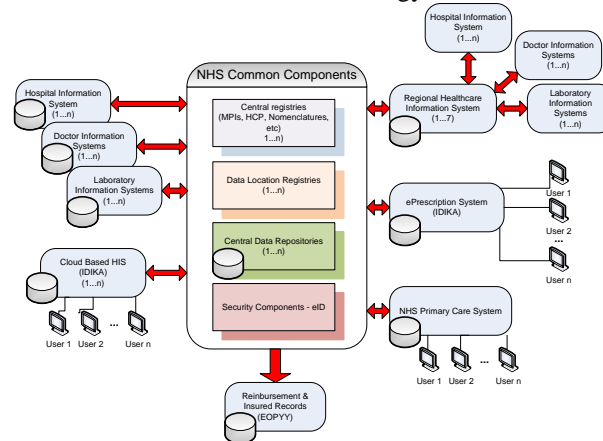


Figure 2: Interoperability Architecture model.

Specific elements of the implementation architecture shown in Figure 3 is based on technical interoperability centers based on the IHE Cross Enterprise Document Sharing (XDS) profile, with HL7 Clinical Document Architecture (CDA) payloads and W3C web services transport. The Registry-Repository Model (e. g. IHE XDS) provides a solution to the problem of locating information quickly at a regional and national level. XDS and XDS.b support **federated document repositories** and a document registry to create a longitudinal record of information about a patient within a given clinical affinity domain. HL7 CDA documents form the common coin of exchange. Mapping to the Exchange Content Model, CDA documents carry clinical content. The IHE Audit Trail and Node Identification (ATNA) profile supports audit of information exchange. In addition, HL7 FHIR DSTU 1 was assessed and used to create a healthcare encounter report facility to collect data from multiple sources and populate the patient summary service. HL7 FHIR resources were seamlessly integrated with EU patient summary format, proving the power of HL7 FHIR. The EHR System Functional Model (ISO/HL7 10781:2009), which can also be profiled can help link the functions of information systems to supported integration use cases. Underpinning the architecture is a services based approach, where a service can be defined as specific functionality that can be invoked using defined interfaces that are implementation agnostic – such as web services, REST, JSON, HL7

FHIR or other technologies. Semantic interoperability relies on the reference terminologies used in epSOS Patient Summary pilots mapped to similar national terminologies. Collectively, the above define a standards-based data services fabric or maintenance shop; the **eHealth Platform**. For long-term sustainability, an operational model including standardization, testing and specification tasks is necessary. Point of care systems should be certified and be compliant within a predefined period of time. Edge systems and exchange services support the consent directives for the exchange of health information including recording attaching consent to specific parts of the summary. Document messaging point-to-point shall adhere to XDR/XDM integration profiles, especially in patient mediated scenarios.

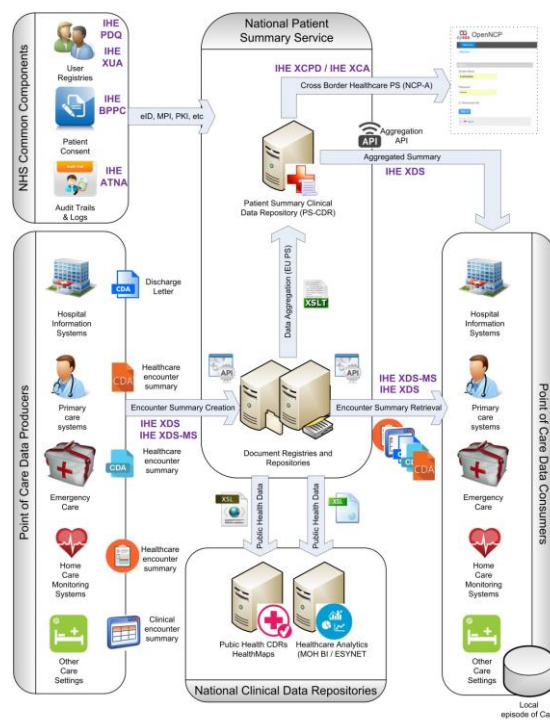


Figure 3: Patient Summary Architecture and relevant IHE profiles

### 3 Results

Two teams worked in parallel to create the infrastructure and interoperability layer needed to implement a national patient summary service. The first team under the health in action initiative monitored by WHO in Greece created the proposed architecture and set of interoperability specifications needed. SOHealth analyzed the specifications and built an initial reference implementation to be tested by IDIKA SA. The use of HL7 CDAs allowed more than one end user application can be built to visualize medical content in response to physician requests. As a minimum GUI, the epSOS CDA display tool was used to validate proper conversion from FHIR to epSOS compatible HL7 CDA format, ensuring compatibility with EU guidelines for patient summary. In the reference implementation, three main sources of information were incorporated in this context: (a) ePrescription data (dispensed drugs, etc) proving input to patient summaries; (b) Hospital

discharge letters use for the encounter reports; (c) Primary care systems that can import encounter reports. Interoperability integration via the HL7 FHIR server took more than 2 weeks of work proving the viability of the architectural approach. The patient summary case study can be seen as the first step to implement similar services in other domains (laboratory, radiology, telecare, etc.). The Greek Patient Summary case was documented in eStandards D.4.1 (<http://www.estandards-project.eu/index.cfm/deliverables>) as EU best practice dealing with multiple standards to achieve end to end interoperability.

#### 4 Discussion

The patient summary implementation pilot revealed two main challenges regarding concurrent standards and specifications as reflected in the implemented component systems: (a) lack of proper terminologies in Greece; (b) immaturity of information systems into following interoperability architecture. From the terminology perspective, patient summary clinical data were mapped to epSOS Master Value Catalogue (MVC). Where terminologies or codifications were inexistent, the terms of epSOS were adopted. Where other terminologies were used, they were mapped to epSOS MVC. To address the immaturity of information systems, a possible approach based on HL7 FHIR, seems the easiest to adopt. This requires minimal implementation skills and effort from point of care systems. Complexity is hidden from edge systems that handle medical information at the point of care allowing easy access to point of care information. A server-side FHIR server allows the proper transformation of FHIR resources to HL7 CDA documents. This approach allows compatibility with the Patient summary guideline facilitating cross-border patient summary exchange. Step by step, an IHE XDS network will be established to allow document discovery and exchange over a National healthcare network. Moving forward, a full OID structure for the CDA documents, and a set of XDS metadata to be expanded for additional use cases.

Three main lessons were gained. First, “*Do not reinvent the wheel*”: use and refine existing profiles and standards HL7 CDA, HL7 FHIR standards and IHE integration profiles. Second, “Follow security and data privacy guidelines to build trust.” eIDAS architecture, STORK eID scenarios, Greek eID infrastructure, EU-friendly patient consent mechanism allow break glass scenarios for unplanned care. Third “*Think big, start small.*” HL7 FHIR resources are interoperability assets that can be easily expanded building interoperability as they mature result of close international collaboration.

Moving from this reference implementation to large scale implementation would take important steps. Long term planning would take into account secure semantic interoperability and governance of infostructures. The Ministry of Health needs to initiate and operate the legal and technical governance in conjunction with the evolving Greek legislation (N4013/2013, N4238/2014). Incentives delivered at the point of care would also facilitate large scale eHealth deployment.

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