The Chartered Institute for IT

Faculty of Health and Care

Health Data Exchange Formats: IPS, EuropeanEHRxFormat and a Global-EHR

Henrique Martins, MD PhD MLaw

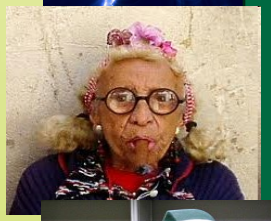
Associate Professor at ISCTE (Lisbon) – Coordinator of the XpanDH project

Senior Consultant in Digital Health and Innovation - WHO Athens Quality of Care and Patient Safety Office

European EHRxFormat

What is the context of integration?…

XXI Century Health & Main Advanced Digital Health Challenges



+ age

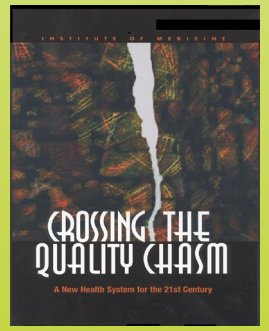
+ tech

+ Knowledge

Data - Open and FAIR principles, (the NEW GOLD)
Information – Sharing is key (content interoperability)
Knowledge – is rare (involves Hybrid-I and Advanced-I)
Meta-knowledge – network and strategy (know who knows what and how it knows)

Aims for Health Care Delivery System

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



From vertical to collaborative care –
"digital patient as the "integrator"/centre of integration

- **Digital Inclusion** - Capacity to ensure advanced tech is equitably accessible to organizations/citizens
- **Minimally disruptive Tele/meta health services –** Tele/metahealth services that offer high Quality-of-Care
- **Trustworthy Digital Clinical Services –** Including mHealth APPs; AI-based Solutions; Digital Therapeutics
- **Health data economy & health innovation –** Health data spaces for data exploration and care integration/innovation
- **Digital sovereignty & sustainability –** Creation of digitally advanced infrastructures and processes that cybersecurity, governmental sovereignty and cost-effective architectures

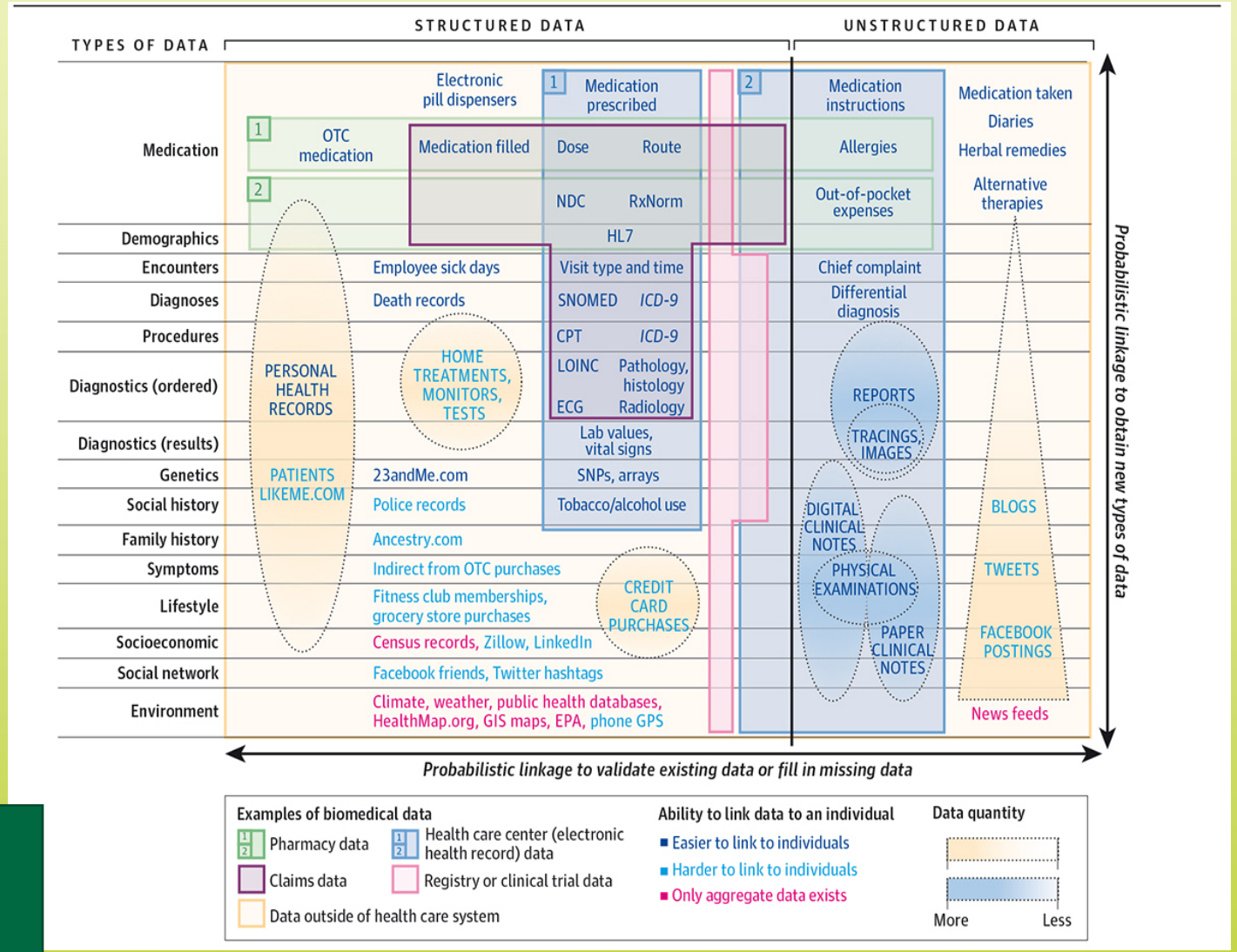
- (FOR EU) – **Adoption and Adaptation to the Reg. European Health Data Space** (2024---2030) including: European EHR Exchange format, wellness APPs, Secondary Use of Data

Prof. Dr. Henrique Martins, MD, PhD, FCS-UBI ISCTE-IUL, Consultant QoC Office Athens – www.henriquemartins.eu | Henrique@henriquemartins.eu | hmartins@who.int

What [health data] to integrate?…

Health Data…

- Data about the individual's health and care
- Secondary use data
  - National Registries
  - Data about health professionals capacity/system capacity
- Public Health Data / Indicators
- World/Regional level data that is necessary for health policy, cross-border healthcare, world health



DATA LEVEL *Broad (public health) Data Types*

*Data on Communicable Disease (DCD)
*Data on Non-Communicable Disease (DNCD)
*Data on Health System (DHS)
*Data with Public Health Relevance (DPHR)

in H.Martins STOA European Parliament Report

Source: https://www.openaccessgovernment.org/european-infrastructure-and-health-data-space/83393/

Good example

Healthcare Systems
- Are Complex Adaptive Systems
- Are increasingly integratable
- Can OR not – be patient centric

Hospitals
Primary care settings
Patient's homes
Neighborhoods & Communities
Are each 'their own little ecosystems'

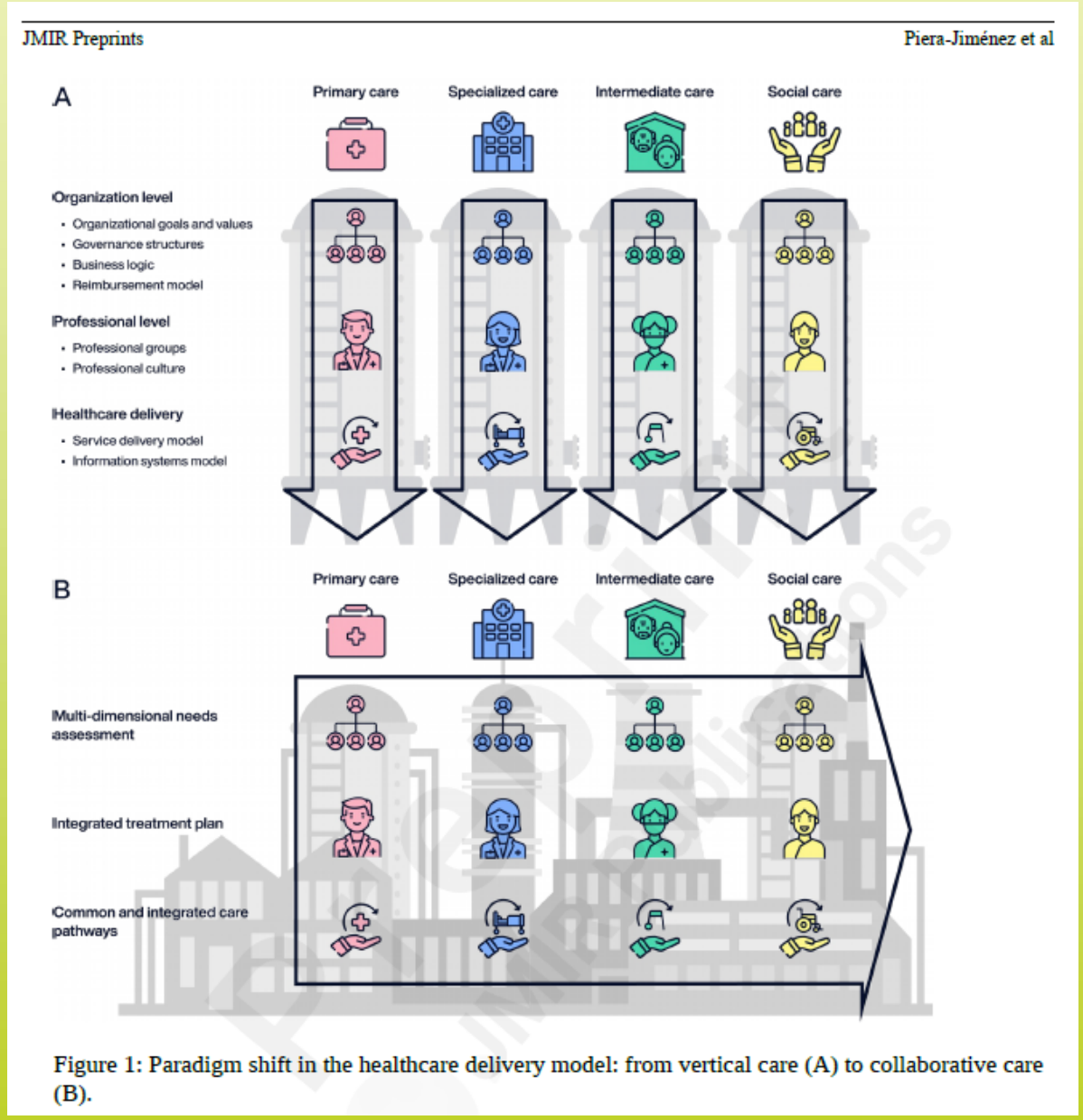


Figure 1: Paradigm shift in the healthcare delivery model: from vertical care (A) to collaborative care (B).

Piera Jiménez J (et. Al) A 25-Years Retrospective of Health Information Technologies Infrastructuring: the Example of Catalonia Region JMIR Preprints. 28/03/2024:58933 DOI: 10.2196/preprints.58933 URL: https://preprints.jmir.org/preprint/58933

Patient as the integrator Personal Health Data Spaces… &

The EHDS – Chapter II; Article 8a 8aa and 8b Right of natural persons to access (….) their personal electronic health data & Recitals (#8 #9)

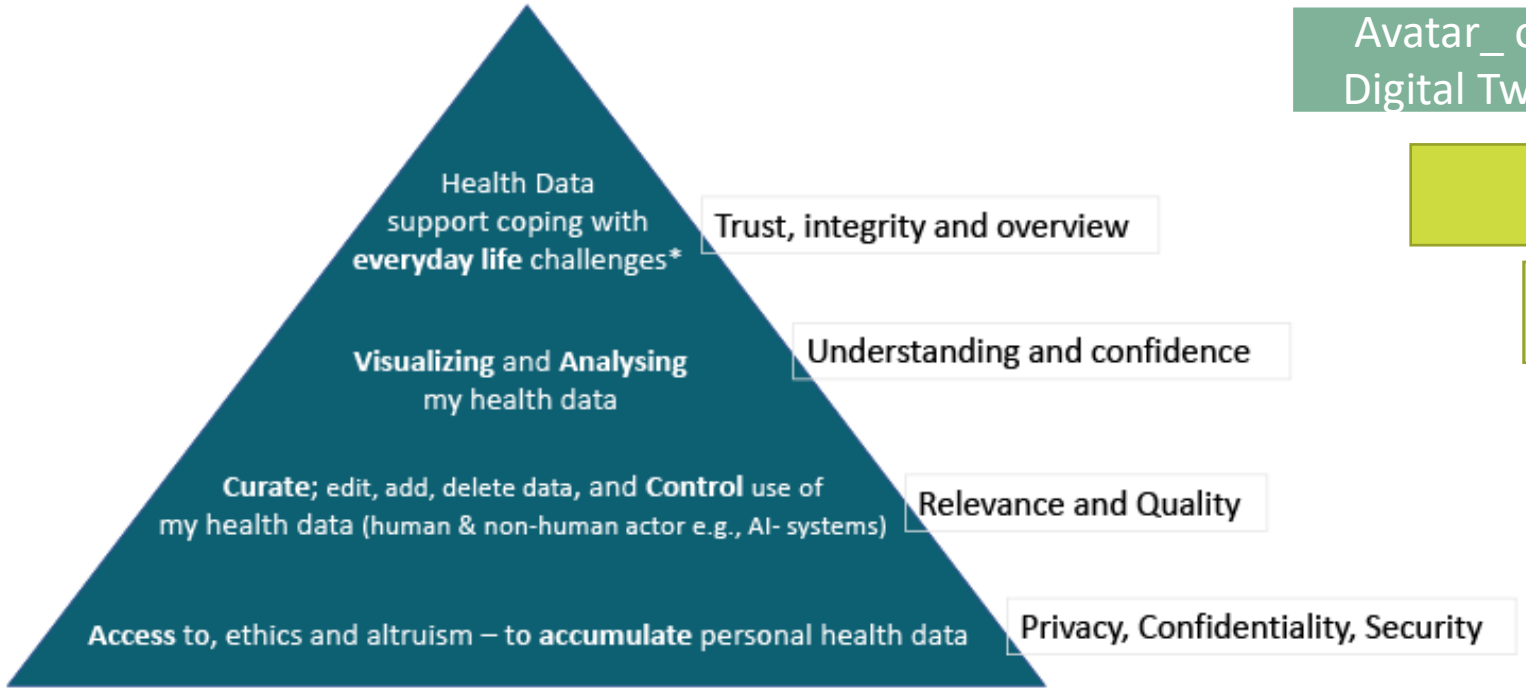


Figure 1.: Personal Health Data Space

Avatar_ of "my data" and/OR of me Digital Twins & AI-based Virtual care

Meta-Health

Tele-Health

Data Self.Determination

"Mobile-Health" Mobility across Care Settings/borders

Health data Activism

Ethical Principals in Digital Health

Digital Inclusion (inc. Explainable AI

People Centric Model to Harness User Value

Reflection on Personal Data Spaces in Transformation of Health and Care

Anne Moen I Professor I University of Oslo and Norwegian Center for eHealth Research I Norway
Catherine Chronaki I Secretary General I HL7 Europe I Belgium
Henrique Martins I Associate Professor I ISCTE Business School I ISCTE-IUL, Lisbon I Faculty of Health Sciences I Universidade da Beira Interior I Covilhã, Portugal
Giovanna Ferrari I Regional Labeling Lead I Global Regulatory Affairs I Global Product Development I Pfizer Limited I UK

https://healthmanagement.org/c/healthmanagement/issuearticle/people-centric-model-to-harness-user-value-personal-data-spaces-in-transformation-of-health-care

XpanDH

The European Context (pre Regulation)

and

With the European Health Data Space regulation (2024---)

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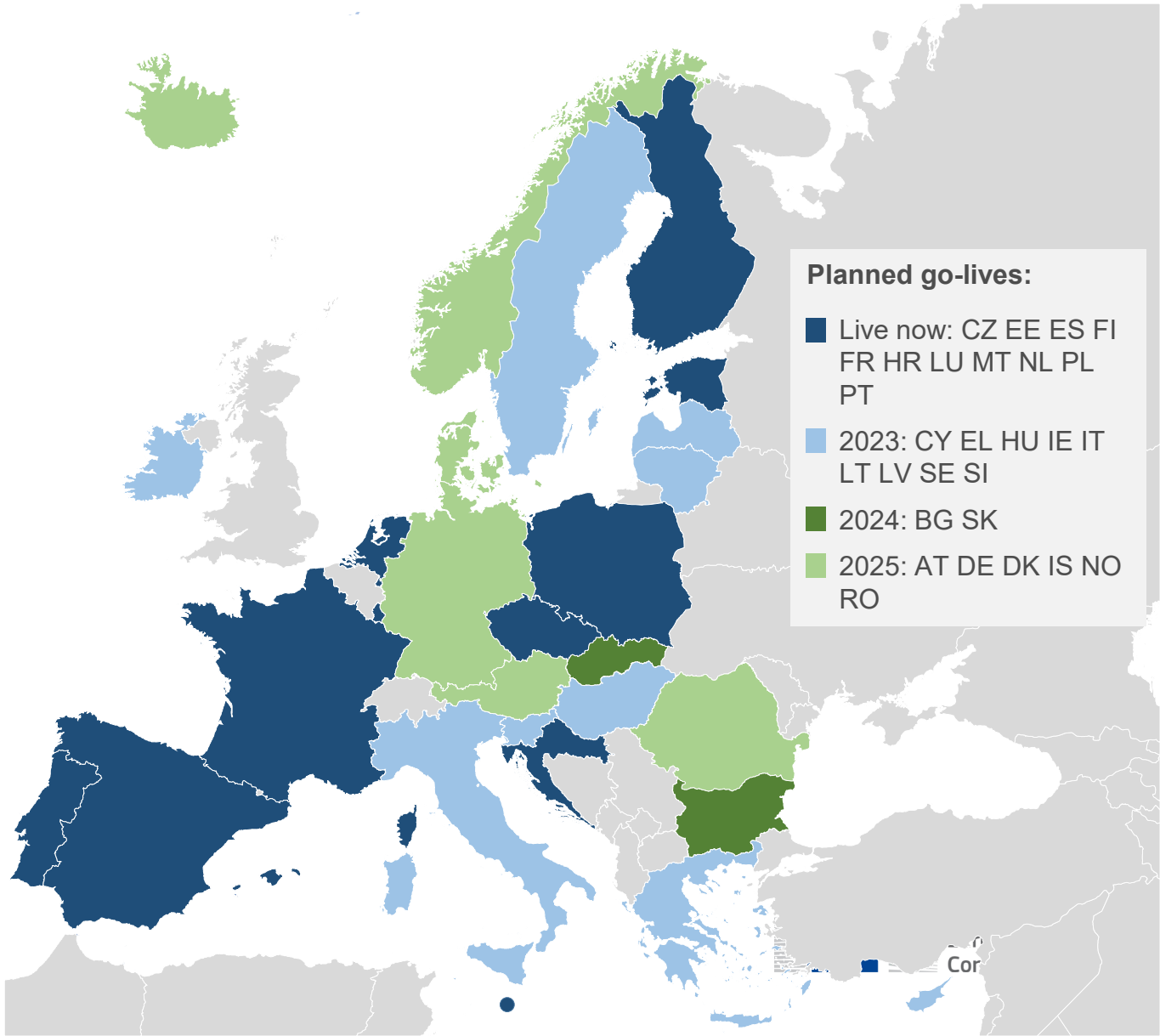
MyHealth@EU state of play

MyHealth@EU is the existing infrastructure that connects healthcare providers in 11 Member States.

It allows them to exchange health data such as Patient Summaries and ePrescriptions.

These services will be expanded to include lab results and other types of health data.



Cross-border e-Prescription in action

My Health @ EU
eHealth Digital Service Infrastructure
A service provided by the European Union

Illustration based on materials from: THL/FI

MyHealth@EU timeline

My Health @ EU
eHealth Digital Service Infrastructure
A service provided by the European Union

ePrescription

EE HR FI PT

IT LT LU RO HU SE BG ES EL CY SI AT DK PL CZ IE LV NO

PT CZ HR LU MT

FR ES NL HU EL IE EE FI IT CY

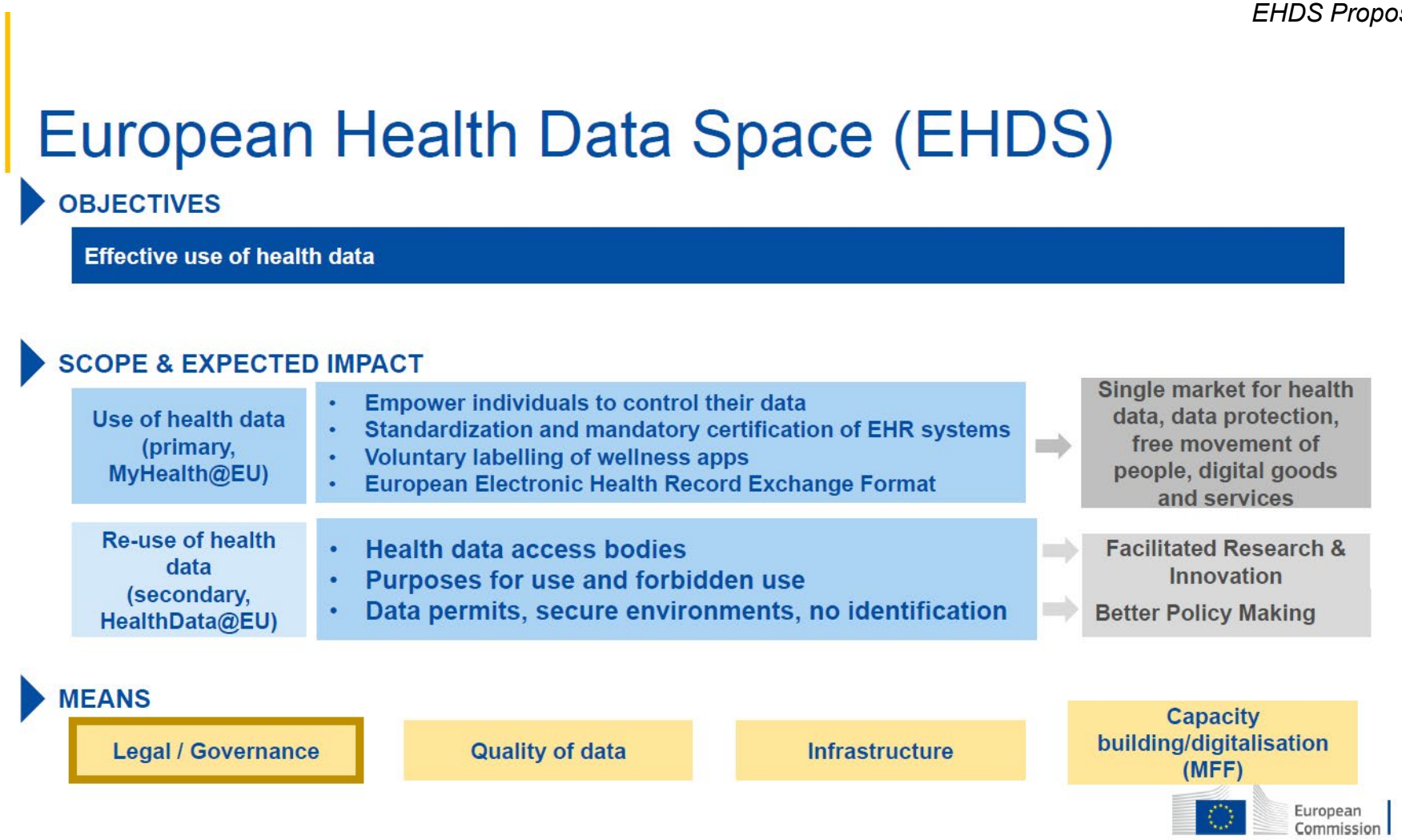
LV LT SI BG NO IS SK DK DE

Patient Summary

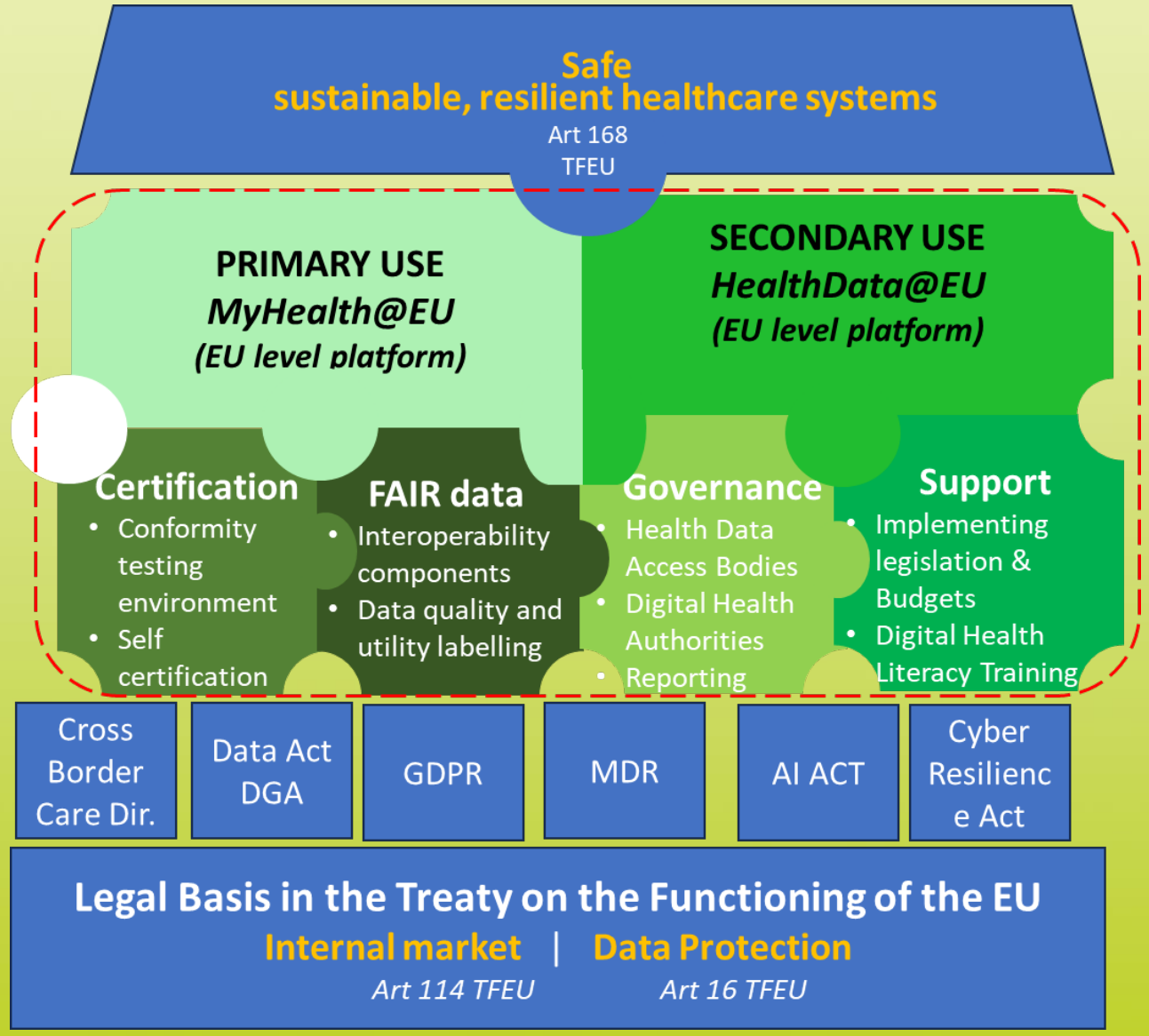
Timelines are approximate and subject to change

The European Health Data Space is a health specific ecosystem comprised of rules, common standards and practices, infrastructures and a governance framework

EHDS Proposal published 03/05/2022

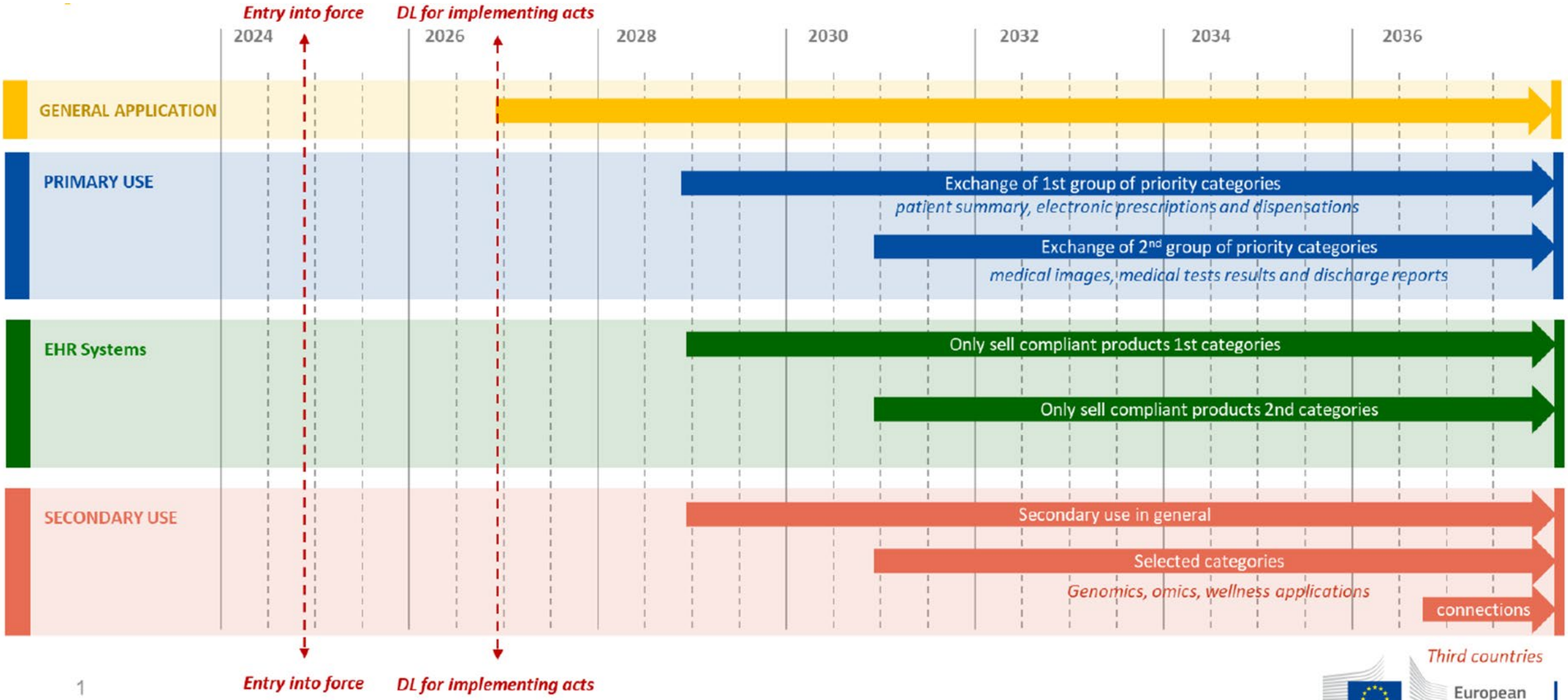


The European Health Data Space Regulation



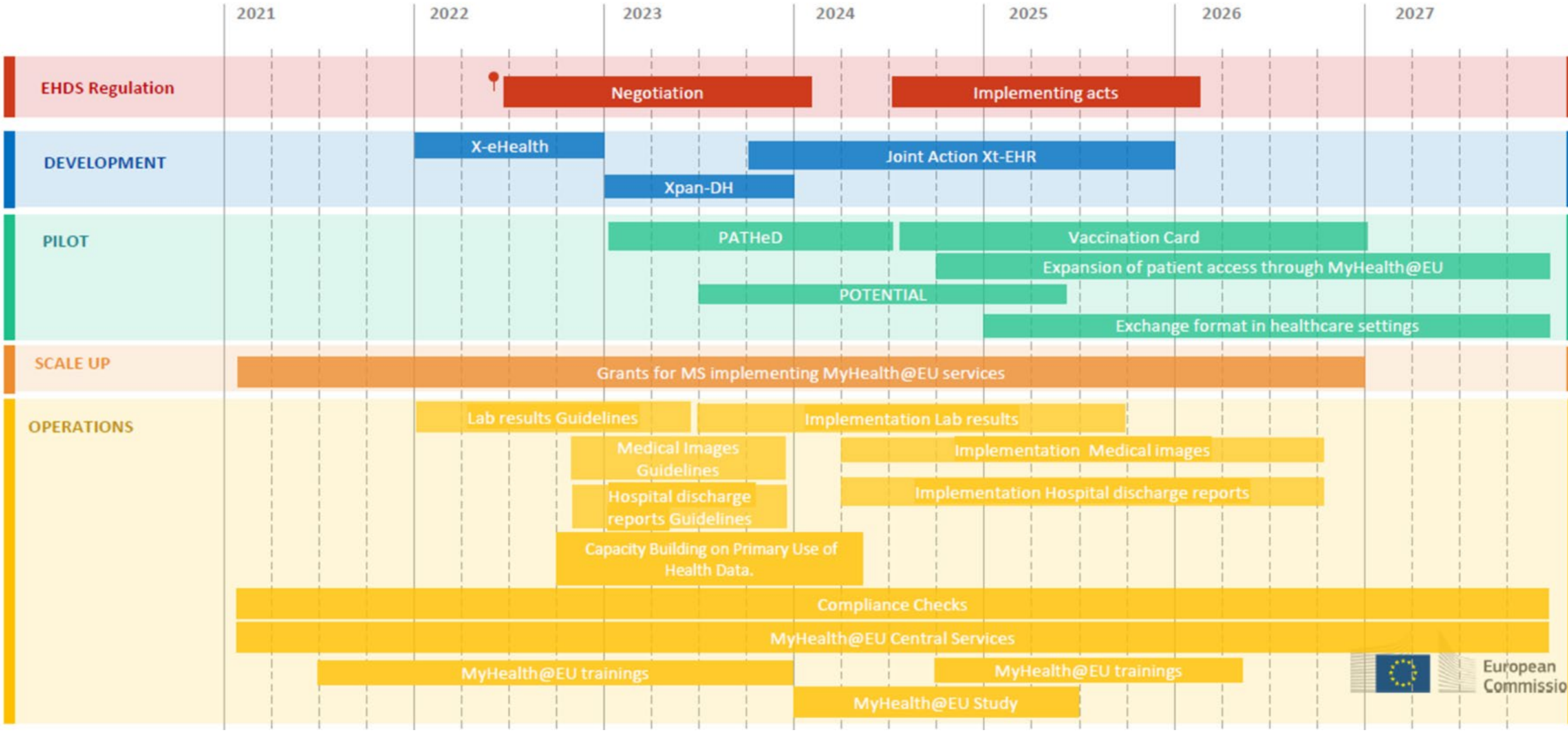
- Founded on the Treaty objectives of building and supporting the internal market, while protecting the privacy of the individual patient, and the right of each Member State to organise its own healthcare system.
- Promoting and supporting the use of data in the provision of healthcare, including across EU borders.
- Unleashing the power of secondary use health data to drive research and innovation, evidence-based policy making and statistical analysis.
- Providing building blocks to ensure data is FAIR, based on common certification systems and subject to a robust governance system, supported by EU level implementing legislation and budgetary support
- Building on the rights established in GDPR, respecting the Data Act and Data Governance Act, re-using values and certifications from the MDR and AI Act, diving security and cyber resilience and supporting cross border care.

EHDS Timelines



European Commission

EHDS Implementation time is NOW



XpanDH

Expanding Digital Health through a pan-European EHRxF-based Ecosystem

Introduction to XpanDH

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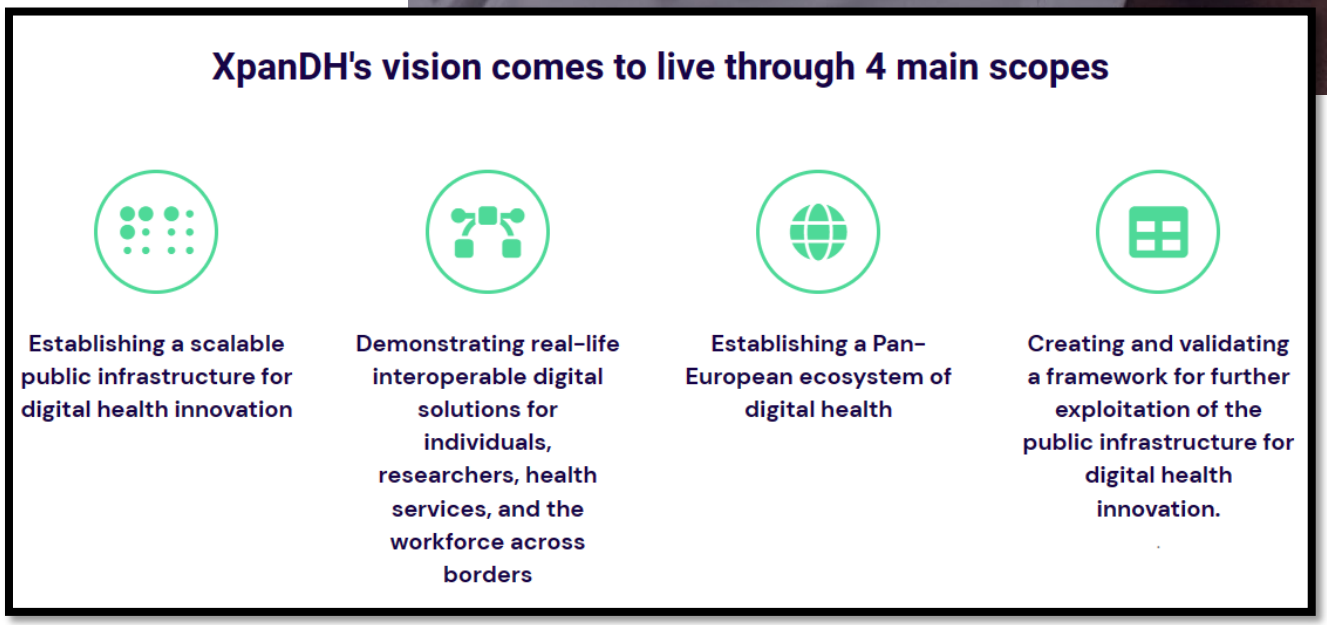
XpanDH Project

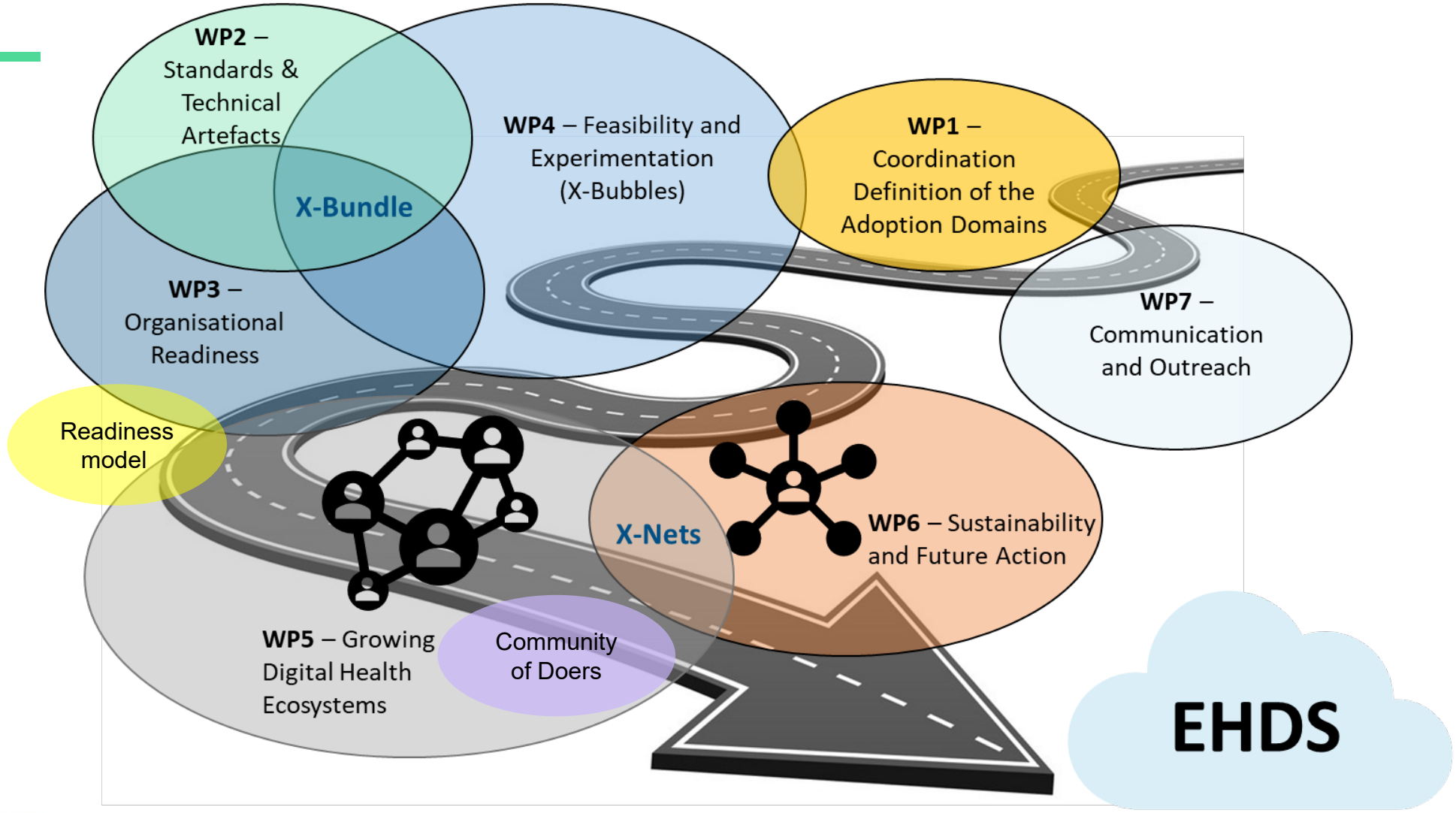
Coordinator:
Henrique Martins
Project manager:
Anderson Carmo
2023-2024



https://xpandh-project.iscte-iul.pt/

Funded by the European Union

XpanDH overview



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The EHDS – Chapter I; Article 1

Subject matter and scope

1. This Regulation establishes the European Health Data Space ('EHDS') by providing for common rules, standards, infrastructures and a governance framework with a view to facilitating access to electronic health data for the purposes of primary and secondary use of these data.

2. This Regulation:

(a) specifies and complements the rights laid down in Regulation (EU) 2016/679 of natural persons in relation to the primary and secondary use of their personal electronic health data;

(b) lays down common rules for electronic health records systems ('EHR systems') in relation to two mandatory software components, namely the 'European interoperability component for EHR systems' and the 'European logging component for EHR systems' as defined in Article 2(2), points (nc) and (nd), and wellness applications that claim interoperability with EHR systems in relation to those two components in the Union for primary use;

(c) lays down common rules and mechanisms for primary and secondary use of electronic health data;

(d) establishes a cross-border infrastructure enabling the primary use of personal electronic health data across the Union;

(e) establishes a cross-border infrastructure for the secondary use of electronic health data;

(f) establishes governance and coordination on national and European level for both primary and secondary use of electronic health data.

Source EP text approved 24.4.2024: https://www.europarl.europa.eu/doceo/document/TA-9-2024-04-24_EN.html#sdocta18

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The EHDS – Chapter II; Article 5 n.1

Priority categories of personal electronic health data for primary use

1. For the purposes of this Chapter, where data is processed in electronic format, the priority categories of personal electronic health data shall be the following ▌:

(a) patient summaries;
(b) electronic prescriptions;
(c) electronic dispensations;
(d) medical imaging studies and related imaging reports;
(e) medical test results, including laboratory and other diagnostic results and related reports;
(f) discharge reports.

The main characteristics of the priority categories of personal electronic health data ▌ shall be as set out in Annex I.

Member States may provide by virtue of national law that additional categories of personal electronic health data shall be accessed and exchanged for primary use pursuant to this Chapter. The Commission may, by means of implementing acts, lay down cross-border specifications for these data categories pursuant to Article 6(-1a) and Article 12(8).

(2022 PROPOSED TEXT). (d)medical images and image reports; (e) Laboratory results;

Source EP text approved 24.4.2024: https://www.europarl.europa.eu/doceo/document/TA-9-2024-04-24_EN.html#sdocta18

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The EHDS – ANNEX I

Main characteristics of **priority categories of personal** electronic health data **for primary use**

Electronic health data category	Main characteristics of electronic health data included under the category
1. Patient summary	Electronic health data that includes important clinical facts related to an identified person and that is essential for the provision of safe and efficient healthcare to that person. The following information is part of a patient summary: 1. Personal details 2. Contact information 3. Information on insurance 4. Allergies 5. Medical alerts 6. Vaccination/prophylaxis information, possibly in the form of a vaccination card 7. Current, resolved, closed or inactive problems ***including in an international classification coding*** 8. Textual information related to medical history 9. Medical devices and implants 10. ***Medical or care*** procedures 11. Functional status 12. Current and relevant past medicines 13. Social history observations related to health 14. Pregnancy history 15. Patient provided data 16. Observation results pertaining to the health condition 17. Plan of care 18. Information on a rare disease such as details about the impact or characteristics of the disease
2. Electronic prescription	Electronic health data constituting a prescription for a medicinal product as defined in Article 3(k) of Directive 2011/24/EU.
3. Electronic dispensation	Information on the supply of a medicinal product to a natural person by a pharmacy based on an electronic prescription.
4. Medical image and image report	Electronic health data related to the use of or produced by technologies that are used to view the human body in order to prevent, diagnose, monitor, or treat medical conditions.
5. Laboratory result	Electronic health data representing results of studies performed notably through in vitro diagnostics such as clinical biochemistry, haematology, transfusion medicine, microbiology, immunology, and others, and including, where relevant, reports supporting the interpretation of the results.
6. Discharge report	Electronic health data related to a healthcare encounter or episode of care and including essential information about admission, treatment and discharge of a natural person.

Source EP text approved 24.4.2024: https://www.europarl.europa.eu/doceo/document/TA-9-2024-04-24_EN.html#sdocta18

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XpanDH

What is it, a “format”?

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European EHR Exchange Format Definition

The Format definition

The **European Electronic Health Record Exchange Format** (or "The Format") is a **set of requirements and technical specifications**, as well as endorsed support materials, **targeted at ensuring the interoperability of electronic health record systems** following the Regulation on the **European Health Data Space** and other applicable law.

It is designed to **enable the exchange of personal electronic health data** between two or more EHR systems, other digital health applications or medical devices **and support interoperable capture and reuse in a meaningful way**.

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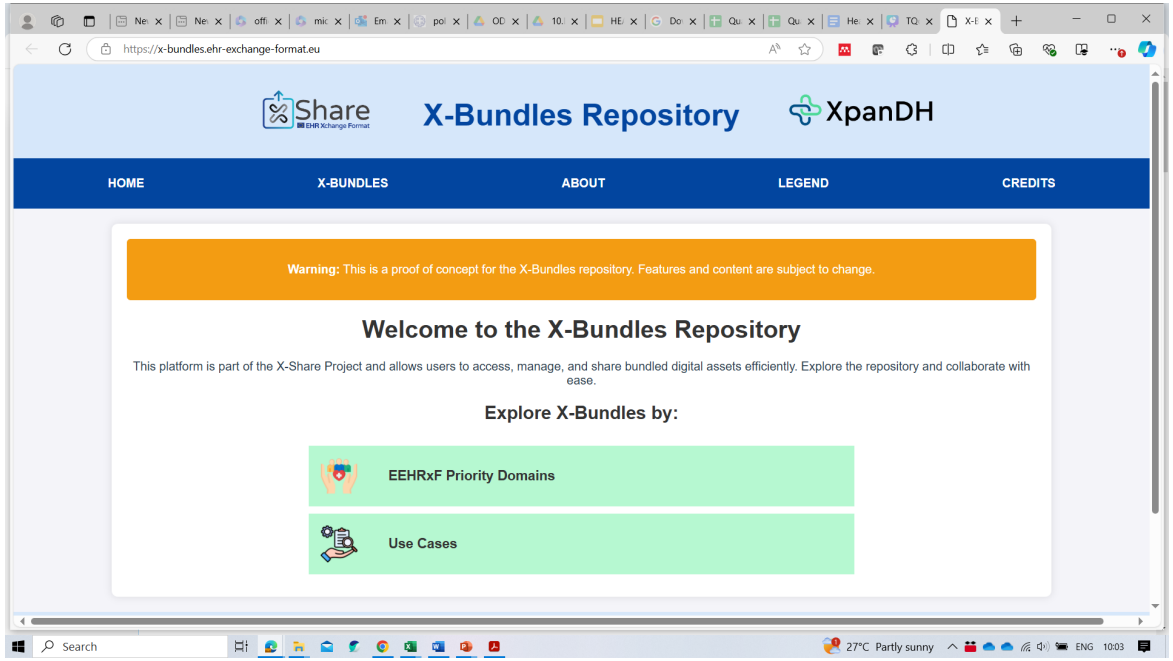
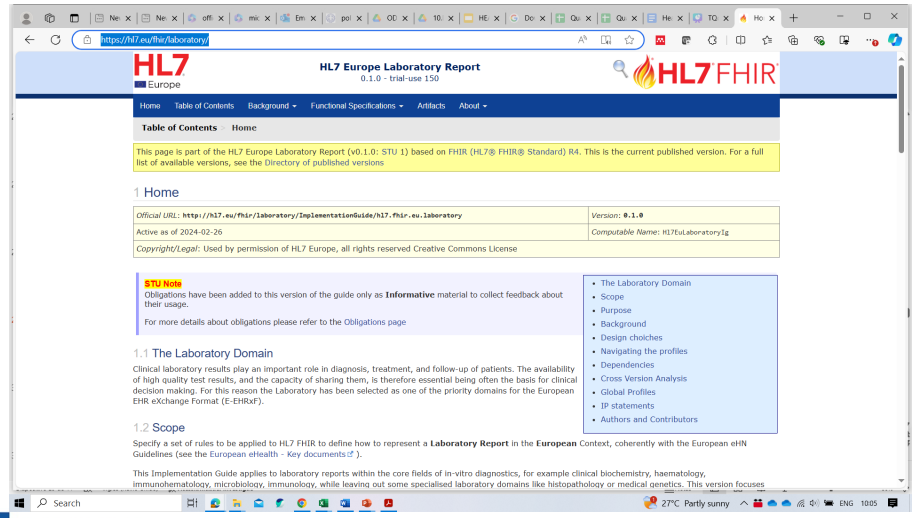
Electronic health data category	EEHRxF	Electronic health data category	EEHRxF
Patient summary (CEN/TS 17288:2020)	Electronic health data that includes important clinical facts related to an identified person and that is essential for the provision of safe and efficient healthcare to that person. The following information is part of a patient summary: 1. Personal details 2. Contact information 3. Information on insurance 4. Allergies 5. Medical alerts 6. Vaccination/prophylaxis information, possibly in the form of a vaccination card 7. Current, resolved, closed or inactive problems 8. Textual information related to medical history 9. Medical devices and implants 10. Procedures 11. Functional status 12. Current and relevant past medicines 13. Social history observations related to health 14. Pregnancy history 15. Patient provided data 16. Observation results pertaining to the health condition 17. Plan of care 18. Information on a rare disease such as details about the impact or characteristics of the disease My health @ EU eHealth Digital Service Infrastructure A service provided by the European Union	**Electronic prescription**	Electronic health data constituting a prescription for a medicinal product as defined in Article 3(k) of Directive 2011/24/EU.
		Electronic dispensation	Information on the supply of a medicinal product to a natural person by a pharmacy based on an electronic prescription.
		Medical image and image report	Electronic health data related to the use of or produced by technologies that are used to view the human body in order to prevent, diagnose, monitor, or treat medical conditions.
		Laboratory result	Electronic health data representing results of studies performed notably through in vitro diagnostics such as clinical biochemistry, haematology, transfusion medicine, microbiology, immunology, and others, and including, where relevant, reports supporting the interpretation of the results.
		Discharge report	Electronic health data related to a healthcare encounter or episode of care and including essential information about admission, treatment and discharge of a natural person.

X-Bundles work in XpanDH and xShare can help understand the X-Format in practice?

- https://x-bundles.ehr-exchange-format.eu/



Home - HL7 Europe Laboratory Report v0.1.0



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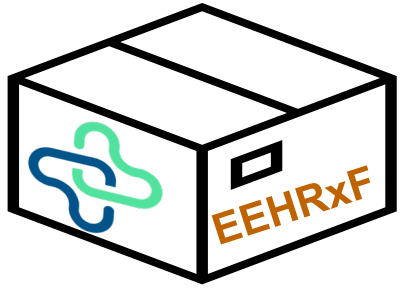
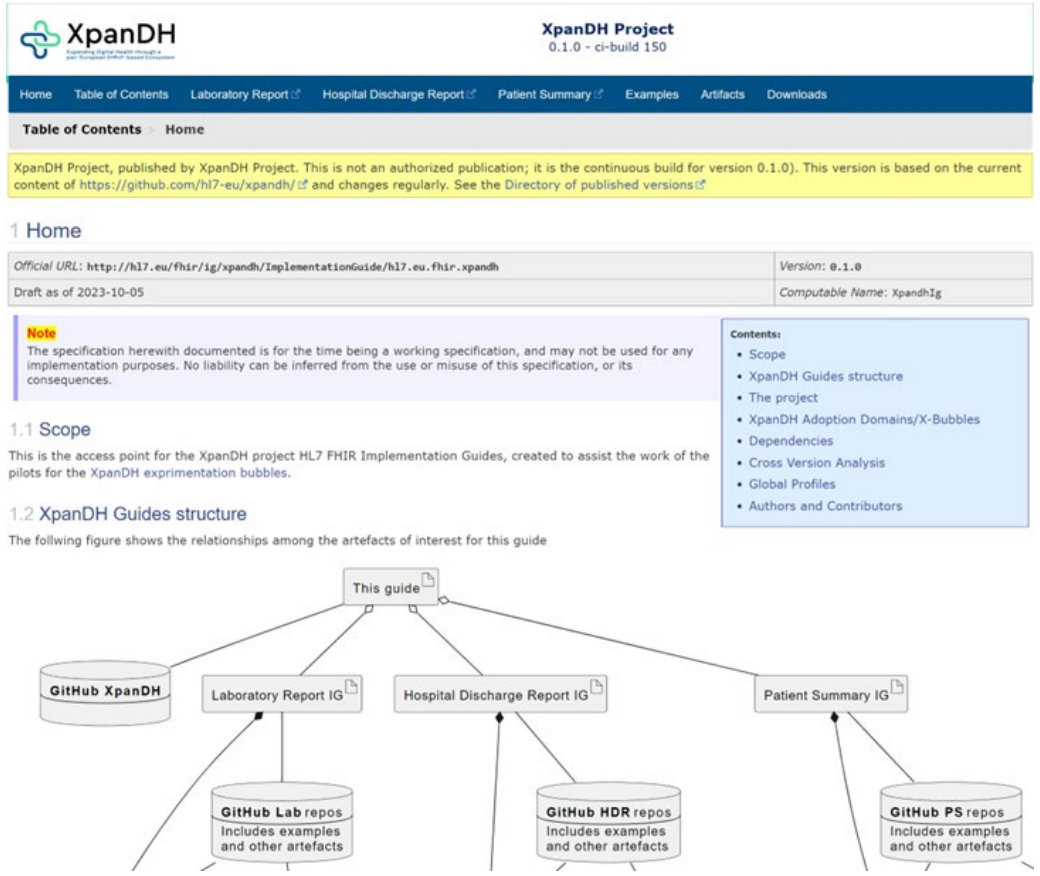
PROF. DR. HENRIQUE MARTINS, MD, PHD, FCS-UBI ISCTE-IUL – WWW.HENRIQUEMARTINS.EU | HENRIQUE@HENRIQUEMARTINS.EU

X-Bundles

The **X-Bundle** correspond to a **group** of **well-defined interoperability assets** that provide the necessary conditions along the Refined eHealth European Interoperability Framework ReEIF six dimensions (Legal, organizational, semantic, technical, cybersecurity and person-readiness/digital capabilities).
It will **support** that a simple or composite **adoption domain be able to be implemented in two or more connecting ends** of an EEHRxF-compatible sharing health data connection.
A single-entry point for the **X-Bundle assets has been created**, it gives access to a coherent ecosystem of **technical specifications**, in the form of **HL7 FHIR IGs**, and github repositories **covering different priority domains** (e.g. Laboratory, Hospital Discharge Report).





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Thanks!

XpanDH website & Social media

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XpanDH
Expanding Digital Health through a pan-European EHRxF-based Ecosystem

EHR @dataspace

Share
EHR Xchange Format

European Commission

Save the date for the:

2nd European EHR Exchange Format Expert Summit in collaboration with the European Commission

Date: 13 November 2024

Format: **Hybrid, In-Person (Brussels) & Online**

#EEHRxFSummit24

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International Patient Summary

Health Informatics TC251

The IPS: a focused PS

Provide an **healthcare summary** for a citizen at the point of care

It is a **minimal** and **non-exhaustive**

It is **specialty-agnostic** and **condition-independent**……but still **clinically relevant**

The IPS: a focused PS

Designed to be **simple**

Usable **any time**, in **any place**; by **any one**

Multi-beneficiaries: Individuals, Healthcare Providers, Society

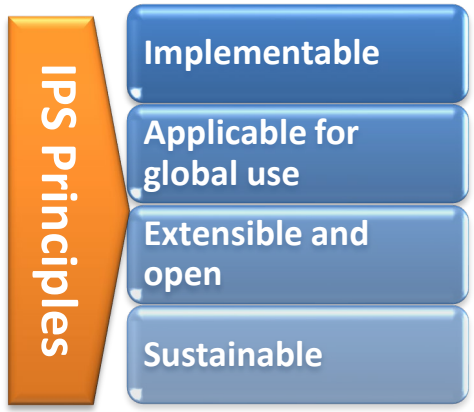
The IPS Project: the HL7 Int. CEN/TC 251 agreement (April, 2017)

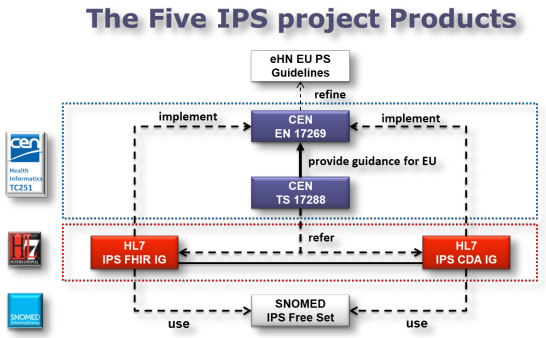
Vision

- *"In order to further the care for citizens across the globe, we agree to **collaborate on a single, common International Patient Summary (IPS)** specification that is readily usable by all clinicians for **the (cross-border) unscheduled care of a patient.**"*

Scope

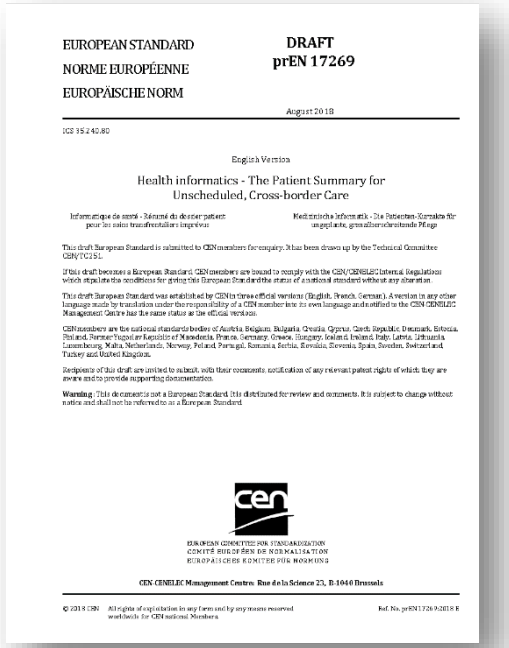
- *"The IPS specification shall focus on a **minimal** and **non-exhaustive** Patient Summary, which is **specialty-agnostic** and **condition-independent**, but **still clinically relevant**."*





CEN IPS EN 17269

The International Patient Summary



EUROPEAN STANDARD
NORME EUROPÉENNE
EUROPÄISCHE NORM

DRAFT
prEN 17269

August 2018

ICS 35.240.80

English Version

Health informatics - The Patient Summary for Unscheduled, Cross-border Care

Informatique de santé - Résumé du dossier patient pour les soins transfrontaliers inopinés

Medizinische Informatik - Die Patienten-Kurzakte für ungeplante, grenzüberschreitende Pflege

This draft European Standard is submitted to CEN members for enquiry. It has been drawn up by the Technical Committee CEN/TC 251.

If this draft becomes a European Standard, CEN members are bound to comply with the CEN/CENELEC Internal Regulations which stipulate the conditions for giving this European Standard the status of a national standard without any alteration.

This draft European Standard was established by CEN in three official versions (English, French, German). A version in any other language made by translation under the responsibility of a CEN member into its own language and notified to the CEN-CENELEC Management Centre has the same status as the official versions.

CEN members are the national standards bodies of Austria, Belgium, Bulgaria, Croatia, Cyprus, Czech Republic, Denmark, Estonia, Finland, Former Yugoslav Republic of Macedonia, France, Germany, Greece, Hungary, Iceland, Ireland, Italy, Latvia, Lithuania, Luxembourg, Malta, Netherlands, Norway, Poland, Portugal, Romania, Serbia, Slovakia, Slovenia, Spain, Sweden, Switzerland, Turkey and United Kingdom.

Recipients of this draft are invited to submit, with their comments, notification of any relevant patent rights of which they are aware and to provide supporting documentation.

Warning: This document is not a European Standard. It is distributed for review and comments. It is subject to change without notice and shall not be referred to as a European Standard.

EUROPEAN COMMITTEE FOR STANDARDIZATION
COMITÉ EUROPÉEN DE NORMALISATION
EUROPÄISCHES KOMITEE FÜR NORMUNG

CEN-CENELEC Management Centre: Rue de la Science 23, B-1040 Brussels

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Ref. No. prEN 17269:2018 E

...**formalises the dataset** required to share information about the medical background and history of a patient ….

.. It uses the **European guidelines** (version 2, November 2016) as an **official source** for the requirements….

The dataset is **minimal and non-exhaustive** <…> **specialty-agnostic, condition-independent** and usable by all clinicians for the **unscheduled care** of a person…

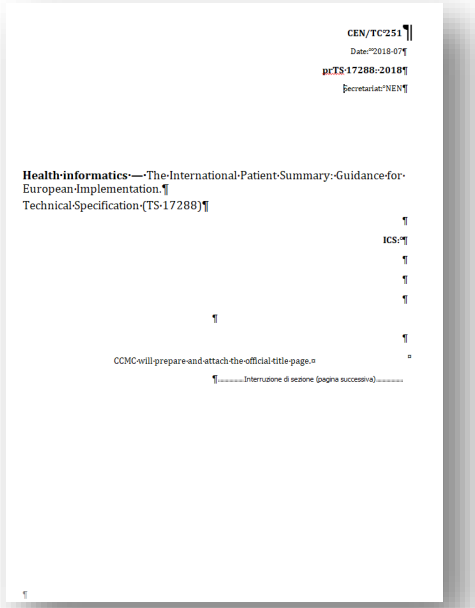
…**usable as a valuable subset** of data items for **scheduled care**…

It is **implementation independent.**

This international standard does not cover workflow processes of data entry, data collection, the summarisation act nor subsequent data presentation. ..

CEN IPS TS 17288

The International Patient Summary: Guideline for European Implementation



CEN/TC·251¶
Date:·2018-07¶
prTS·17288:2018¶
Secretariat:·NEN¶

Health·informatics·—·The·International·Patient·Summary:·Guidance·for·European·Implementation.¶
Technical·Specification·(TS·17288)¶

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ICS:¶
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CCMC·will·prepare·and·attach·the·official·title·page.¤
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¶ Interruzione di sezione (pagina successiva)

¶

…. provides **European implementation guidance for the International Patient Summary** (prEN 17269).

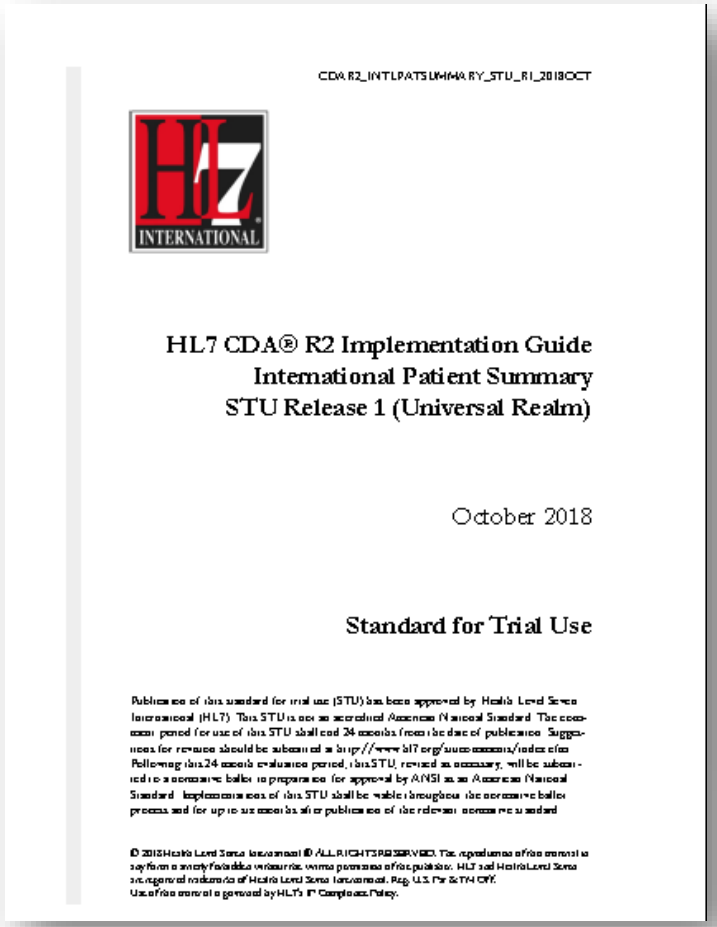
… it is also intended to be **usable for more localised deployment**, <…> as an additional benefit, its **components may be reused** to improve the interoperability of EHRs through **common exchange formats**.

..it addresses: **Jurisdictional requirements**; **Governance, Privacy and data protection** and **Conformance**.

..it includes examples of transport formats…

Out of Scope: recommend a particular delivery platform/service/template.

HL7 IPS CDA Implementation Guide

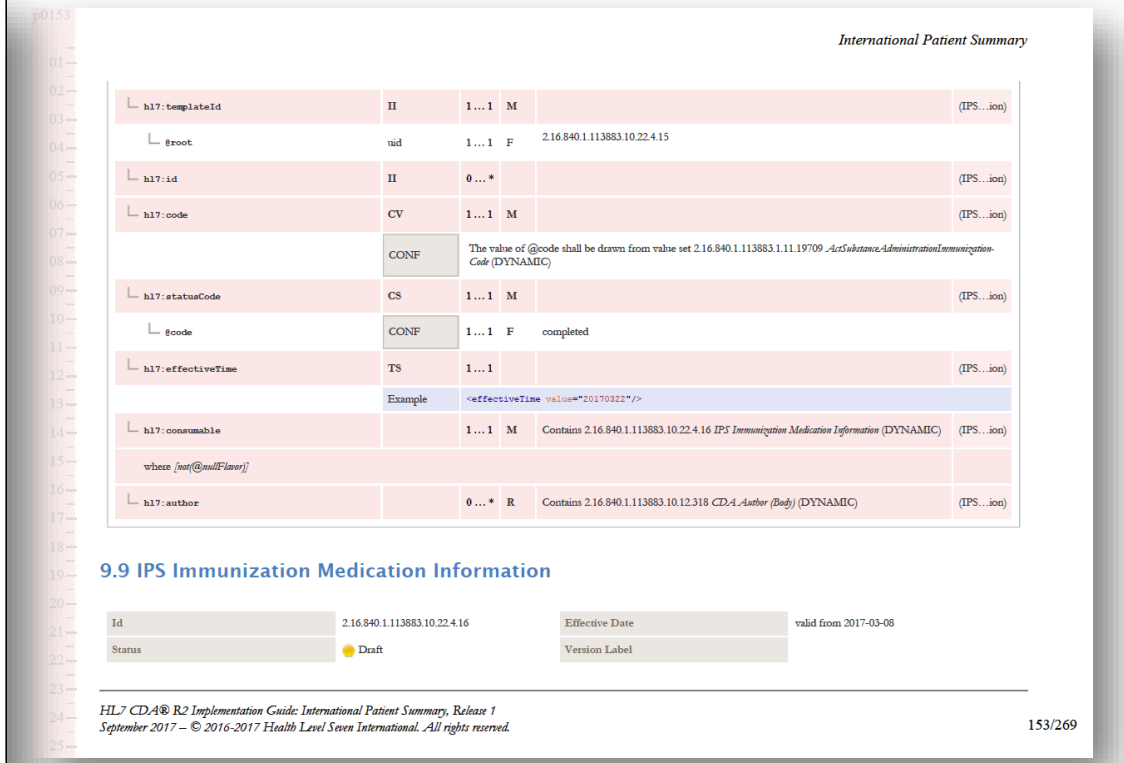


CDA R2_INTLPATSUMMARY_STU_R1_2018OCT

HL7 CDA® R2 Implementation Guide
International Patient Summary
STU Release 1 (Universal Realm)

October 2018

Standard for Trial Use



International Patient Summary

hl7:templateId	II	1…1	M		(IPS…ion)
@root	uid	1…1	F	2.16.840.1.113883.10.22.4.15	
hl7:id	II	0…*			(IPS…ion)
hl7:code	CV	1…1	M		(IPS…ion)
	CONF	The value of @code shall be drawn from value set 2.16.840.1.113883.1.11.19709 *ActSubstanceAdministrationImmunization-Code* (DYNAMIC)			
hl7:statusCode	CS	1…1	M		(IPS…ion)
@code	CONF	1…1	F	completed	
hl7:effectiveTime	TS	1…1			(IPS…ion)
	Example	<effectiveTime value="20170322"/>			
hl7:consumable		1…1	M	Contains 2.16.840.1.113883.10.22.4.16 *IPS Immunization Medication Information* (DYNAMIC)	(IPS…ion)
where *[not(@nullFlavor)]*					
hl7:author		0…*	R	Contains 2.16.840.1.113883.10.12.318 *CDA Author (Body)* (DYNAMIC)	(IPS…ion)

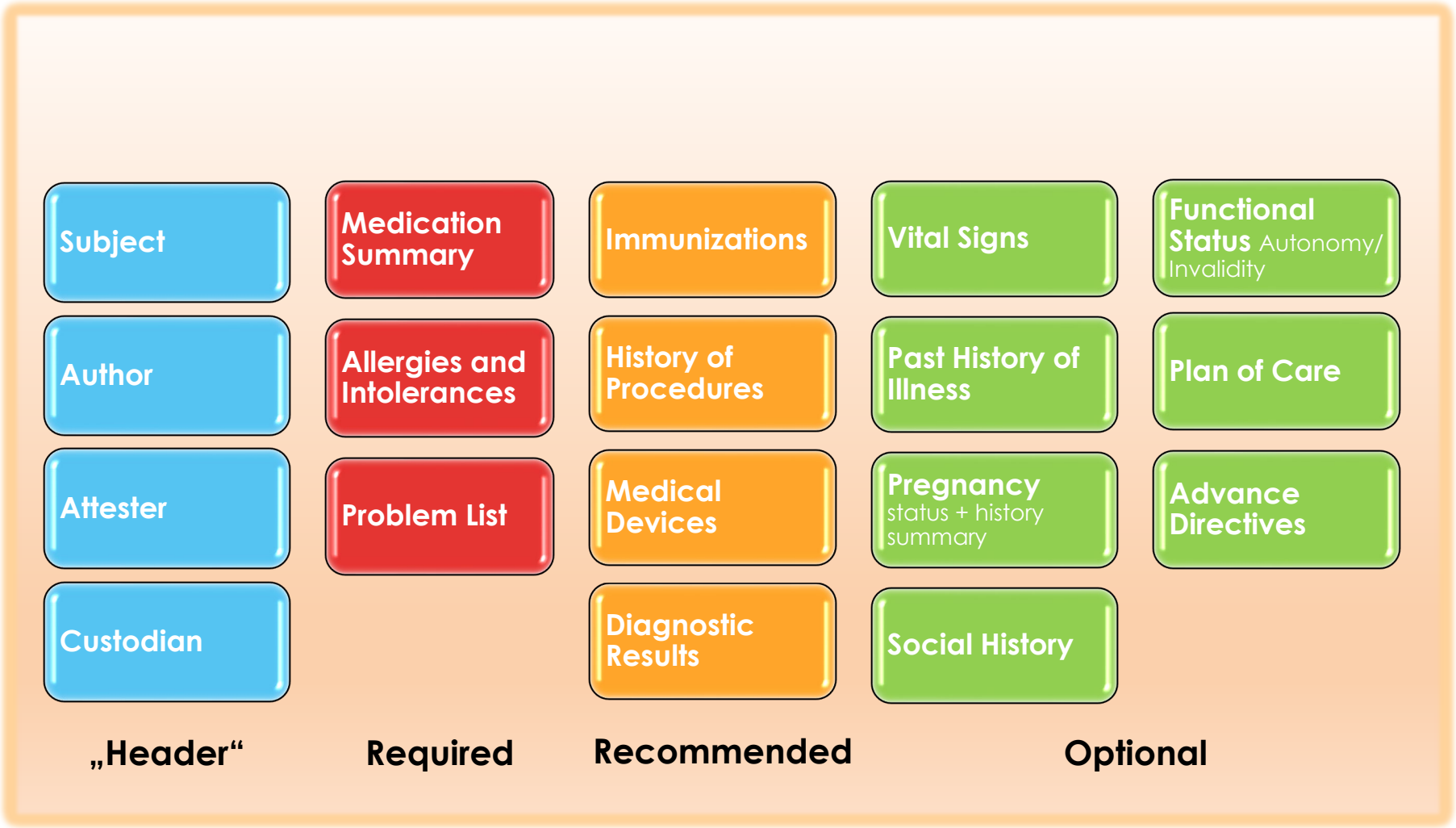
9.9 IPS Immunization Medication Information

Id	2.16.840.1.113883.10.22.4.16	Effective Date	valid from 2017-03-08
Status	Draft	Version Label	

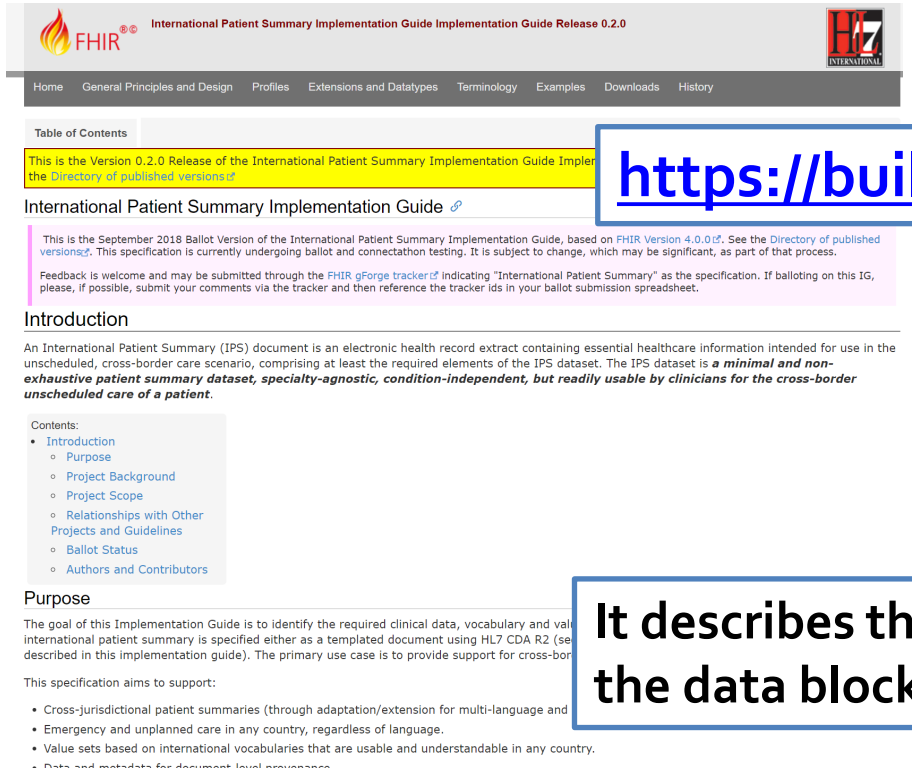
HL7 CDA® R2 Implementation Guide: International Patient Summary, Release 1
September 2017 – © 2016-2017 Health Level Seven International. All rights reserved. 153/269

http://www.hl7.org/implement/standards/product_brief.cfm?product_id=483

IPS Sections



The FHIR IPS IG (STU)



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

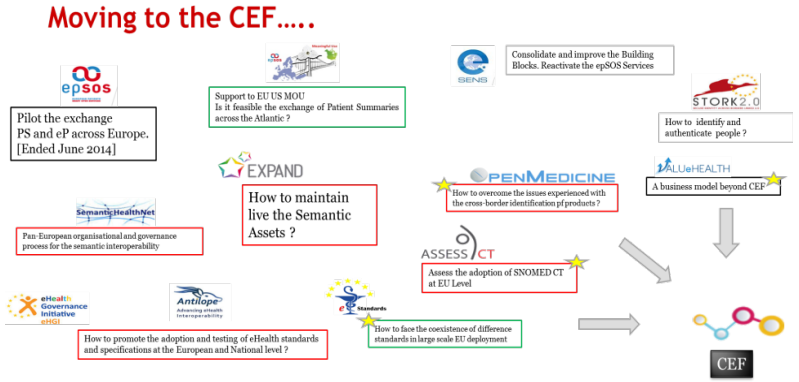
Based on FHIR R4

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

SNOMED CT free subset…

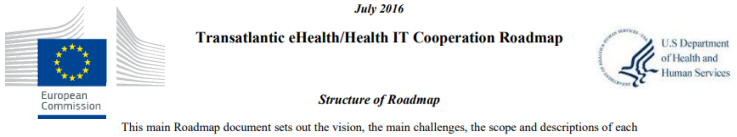
- SNOMED International will(has) release the **Global Patient Set**, or GPS, to support the cross border movement of information, and ultimately health system interoperability.
- The GPS is a controlled list of existing SNOMED CT unique concept identifiers, single descriptions and reference sets, and it will be available to all interested parties at **no cost to users**.
- The **IPS Free set** is a part of the GPS and it includes about **8000 concepts** proposed by the **IPS project**, plus few others used by **eHDSI.**

The IPS comes from a long history …



The **epSOS projects**, cross-border pilot for PS and eP Exchange, 2009-2014... and several others ..to the **eHDSI**

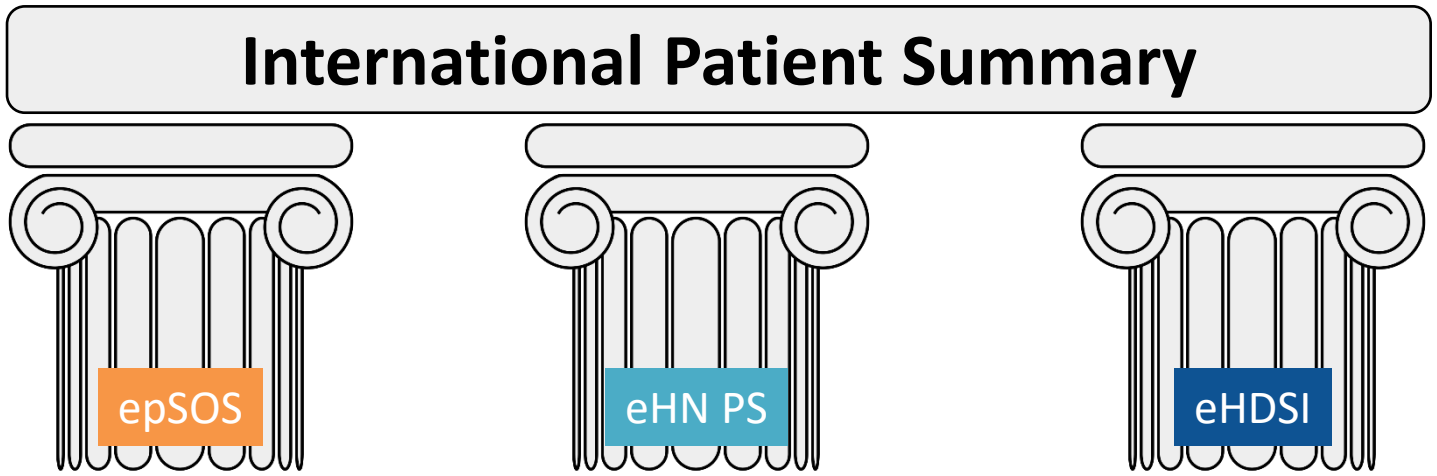
eHealth Network Guidelines
2013-2016

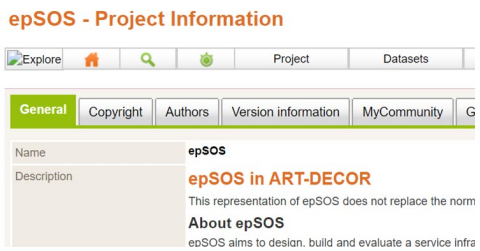


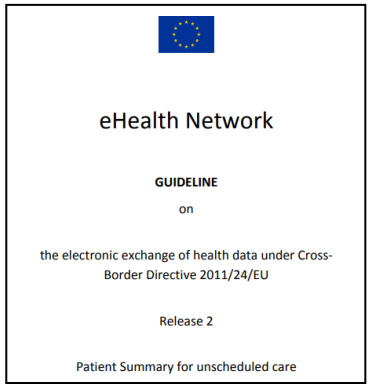
2010 EU US EU/US MoU: ONC Standards and Interoperability Framework (ONC S&I) EU/US eHealth Cooperation Initiative; EU Trillium Project; 2013 The INTERPAS Project, HL7

2015 Transatlantic eHealth/health IT Cooperation Roadmap: foster adoption and further development of the IPS concept.

.. but on solid foundations ...



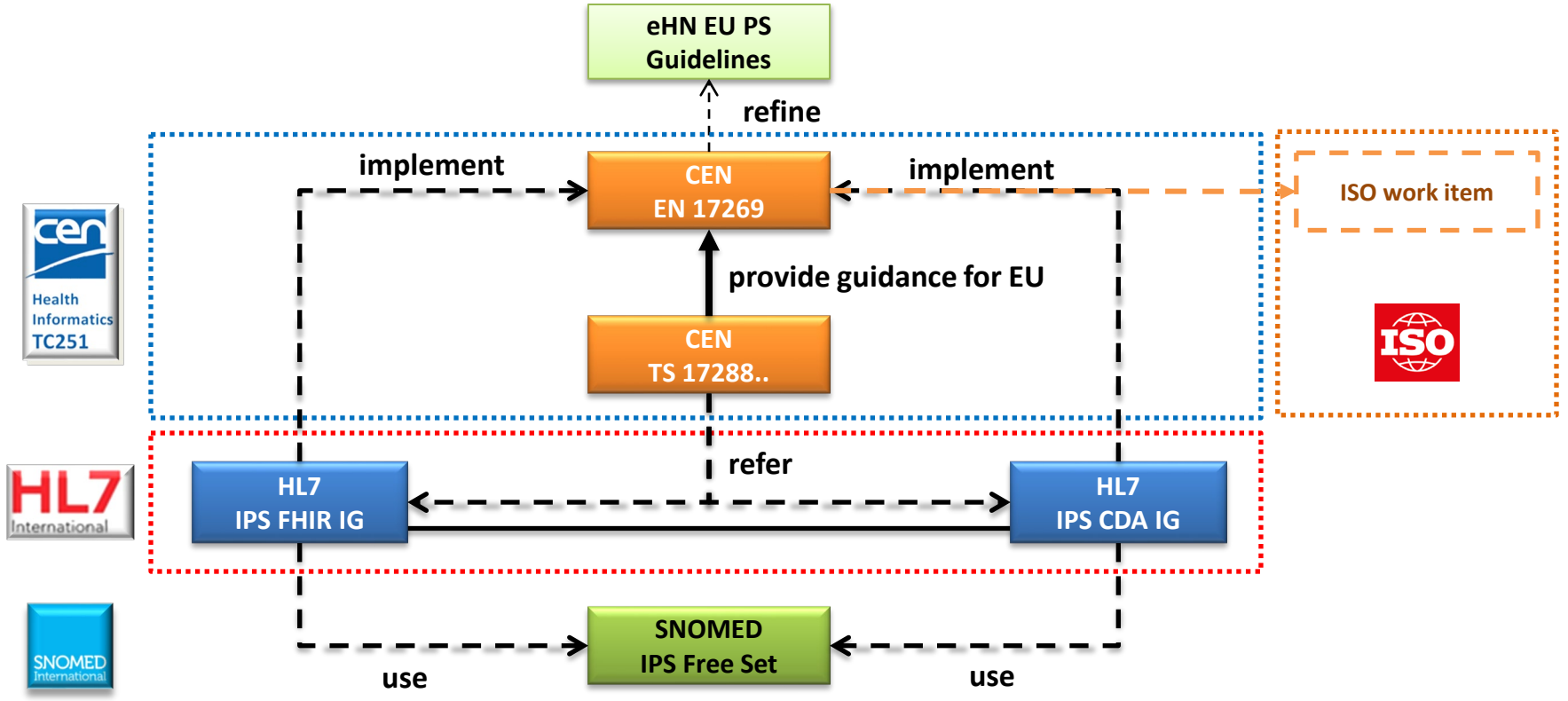




.. in a strong global collaboration …

- **The HL7 and CEN collaboration on IPS has worked superbly well with 4 specifications near completion in just 2 years !**
- **The «IPS SNOMED CT Free Set» by SNOMED International is on the way …**
- **ISO joined the game last April …**
- **..hopefully, to be extended further …**

.. resulting in five (+1) related standards ...



EN 17269: implementation independent content of the IPS
TS 17288: guidelines for establishing an EU IPS service

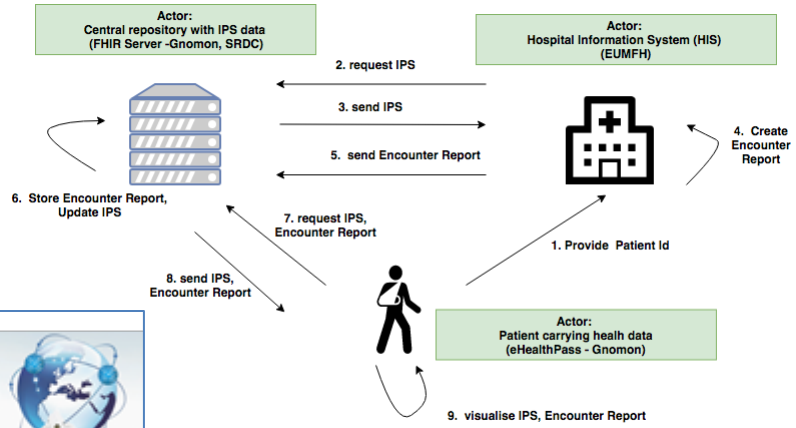
IPS FHIR IG: how to implement the IPS using HL7 FHIR
IPS CDA IG : how to implement the IPS using HL7 CDA

.. applicable and extensible to new cases.

EU ModEX

- Bucharest, 2018 Oct 15-17
- Estonia/Saaremaa, 2019 Apr 11–14

IPSs and **Mobile Field Hospital Encounter Reports** were built on **(HL7 FHIR) IPS resources**



Trillium II

Reinforcing the Bridges and Scaling up EU/US Cooperation on Patient Summary

Department of Health & Social Care

G7 International Patient Summary Roadmap

Published 30 December 2021

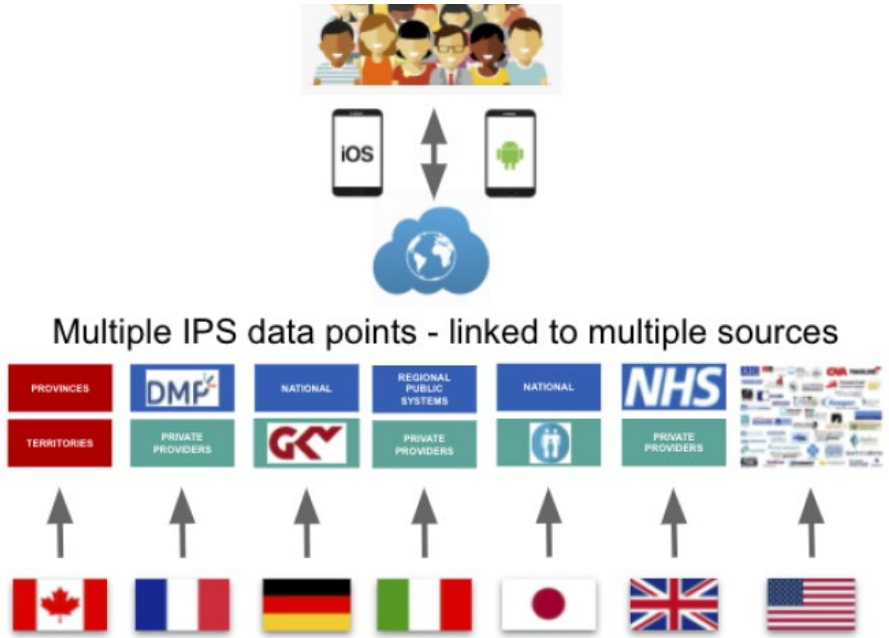


Figure 3: G7-IPS model

G7 Health Ministers' Meeting, communique, Oxford, 4 June, 2021 - GOV.UK (www.gov.uk)

Each G7 country will determine their schedule for uploading additional data blocks. This phased approach will enable each country to add more data when they are able to, but not exclude them from participating in the G7-IPS initiative.

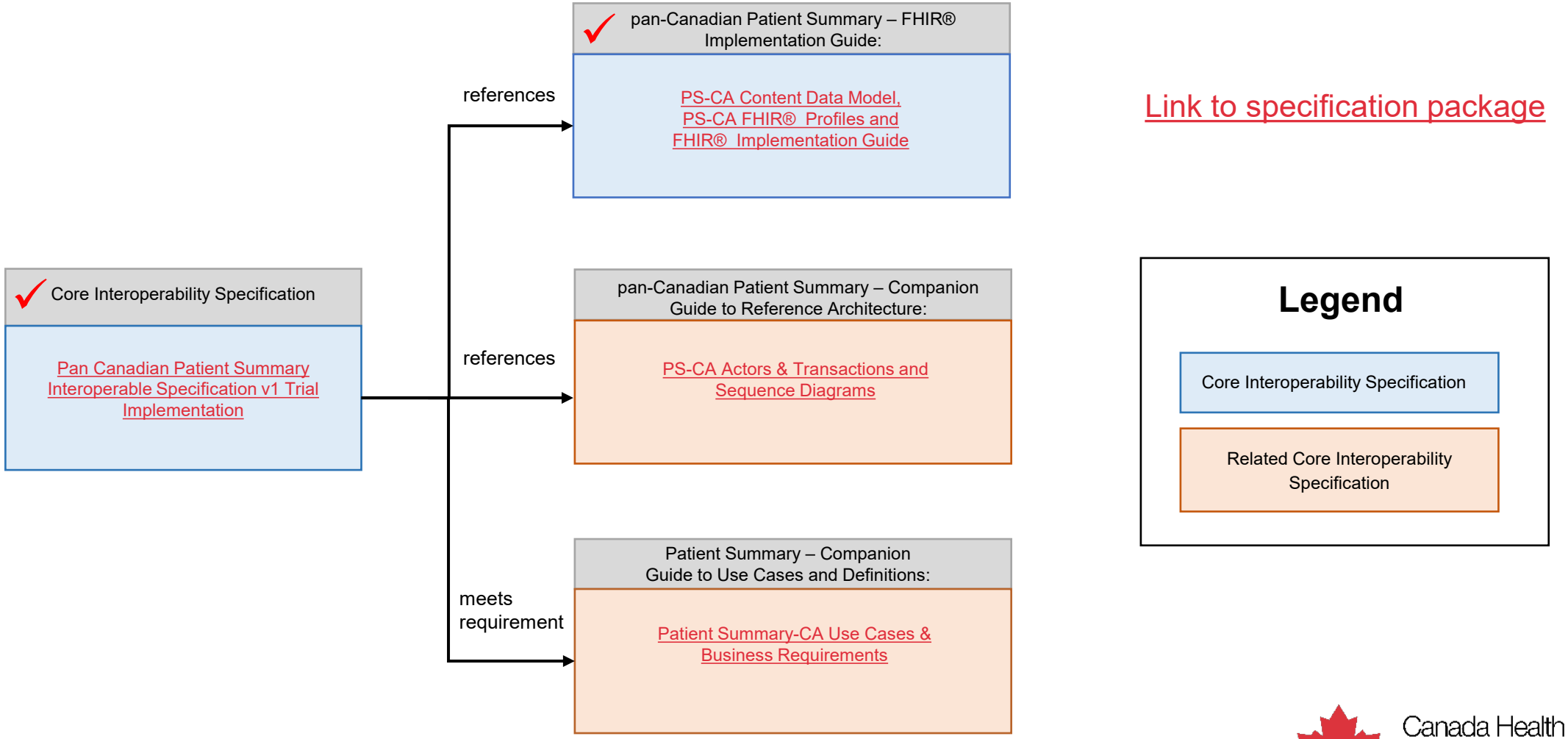
Patient demographics	Allergies and intolerances	Observed conditions	Operative procedures	Social status inc lifestyle factors	Immunisations and vaccinations
Care plans	Health problems inc diagnoses	History of past problems	Medical devices and implants	Vital signs (i.e. BMI, BP)	Current medication
Advance directives (i.e. living wills)	Functional status	History of pregnancy			All medication

Figure 5: ISO 27269:2021 IPS data blocks

Source: https://assets.publishing.service.gov.uk/media/61d82fbd8fa8f505893f1c93/G7-international-patient-summary-roadmap.pdf

Patient Summary-CA Package: Related Documents

The pan-Canadian Patient Summary specification (PS-CA) is a level 2 specification



Link to specification package

Legend

- Core Interoperability Specification
- Related Core Interoperability Specification

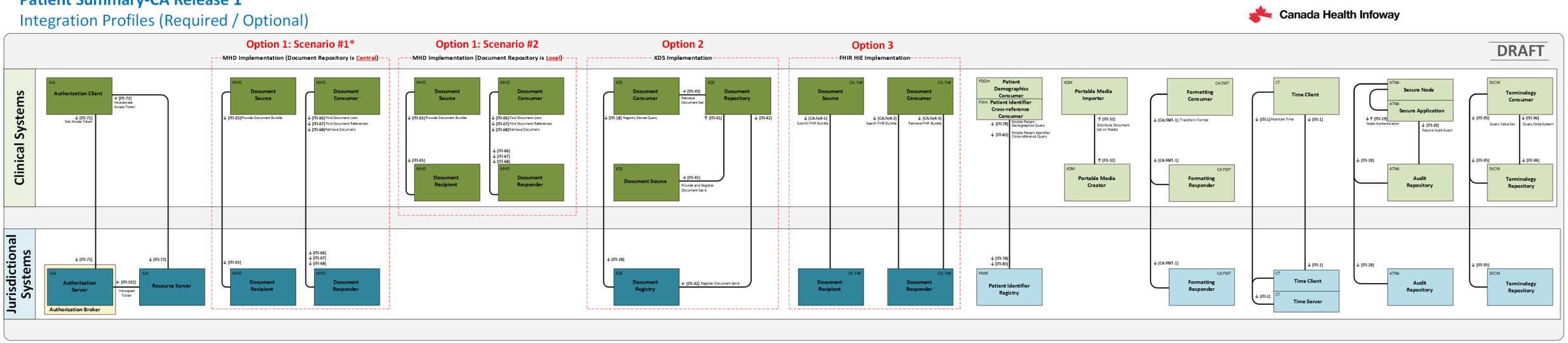
Reference Architecture that Supports PS-CA

An overview of the recommended PS-CA Actors and Transactions

This high-level view contains a superset of profiles that offer alternatives to exchanging the Patient Summary-CA depending on jurisdictional service type and availability. **Mandatory and optional capability support** is described in the sequence diagrams associated with each use case analysis.

Patient Summary-CA Release 1

Integration Profiles (Required / Optional)



IHE Profiles

IUA	Internet User Authorization
MHD	Mobile access to Health Documents
XDS	Cross Enterprise Document Sharing
PMIR	Patient Master Identity Registry
PDQm	Patient Demographics Query for Mobile
PIXm	Patient Identifier Cross-Reference for Mobile
XDM	Cross-enterprise Document Media Interchange
ATNA	Audit Trail and Node Authentication
CT	Consistent Time
SVCM	Sharing Valuesets, Codes and Maps

Canadian National Integration Profile(s)

CA:FMT	Formatting Support Service
CA:FeX	FHIR Exchange Gateway

*Preferred Option

Legend

Clinical System Actors: Mandatory Actors, Optional Actors

Jurisdictional System Actors: Mandatory Actors, Optional Actors

Canada Health Infoway
Inforoute Santé du Canada

The Sequoia Project's Role

The Sequoia Project is the trusted, independent convener of industry and government

Works to address the challenges of secure, interoperable nationwide health information exchange (HIE).

SECURE

INTEROPERABLE

NATIONWIDE

the sequoia project

Global EHR

Why and How of a Global EHR?

A global electronic health record (G-EHR) is achievable with focus, concrete steps, value creation and determination to explore certain elements.

To reach a **truly global digital healthcare system**, however, we need to work much more profoundly and more decisively on real worldwide cross-border eHealth services, like a **global ePrescription system** or sharing of **minimum sets of data (e.g. the ISO International Patient Summary**) and progressively bigger components, such as a vaccination passport, summary or e-cards. For example, medical devices (e.g. insulin infusion pumps, or non-invasive home ventilators) are increasingly globally produced and standardised, yet, the information that they require and generate seems to get 'chained' to local, regional or national health systems, in turn, chaining citizens down to their institutions, often their homes. People fear to travel to a remote location where access to their device or health data is not possible. They know healthcare may not be equally safe, which makes them feel unsafe to travel and 'chained'.

Digital Health Diplomacy refers to the **concentrated international efforts towards supranational interoperability in eHealth/Digital Health**. These may include international agreements for mutual health data transmission, recognition of information systems or common approaches to the use of international standards.

Source: H. Martins 2020:
https://healthmanagement.org/c/healthmanagement/issuearticle/digital-health-diplomacy-in-chained-globalised-health-context

Journal of the American Medical Informatics Association, 00(0), 2021, 1–6
https://doi.org/10.1093/jamia/ocab282
Perspective

Perspective

"Digital Health Diplomacy" in Global Digital Health? A call for critique and discourse

Myron Anthony Godinho [1], Henrique Martins [2,3], Najeeb Al-Shorbaji [4], Yuri Quintana [5,6], and Siaw-Teng Liaw [1]

[1]WHO Collaborating Centre for eHealth (AUS-135), School of Population Health, UNSW Sydney, Sydney, Australia, [2]ISCTE Business School, ISCTE-IUL, Lisbon, Portugal, [3]Faculty of Health Sciences, Universidade da Beira Interior, Covilhã, Portugal, [4]President of the eHealth Development Association, Amman, Jordan, [5]Division of Clinical Informatics, Beth Israel Deaconess Medical Center, Boston, MA, USA, and [6]Harvard Medical School, Boston, MA, USA

https://doi.org/10.1093/jamia/ocab282

What is the Global EHR?

- A global electronic health record (G-EHR) is **a set of interconnected digital systems and services that support the sharing of personal health data across the globe** to support primary use of health data regardless of geographical, jurisdictional and language barriers creating an electronic health record support environment as similar as possible to that experienced by the individual and his/her caregivers in is home country. It is based on standards and is a de facto promotion of data harmonization leading up to a potential "Global Health Data Space" of nominal/anonymized health data for it potential secondary and tertiary use.
- A global electronic health record (G-EHR) is not something utopic. It requires focus, concrete steps, value creation and determination to explore the following elements.
  1) Creating a worldwide voluntary patient and health professionals' registries
  2) Setting up a global regime/governance forum for the advancement of agreements and common creations
  3) Using a common exchange format (possibly inspired in the European EHR exchange format?)
- Source: H. Martins 2020: https://healthmanagement.org/c/healthmanagement/issuearticle/digital-health-diplomacy-in-chained-globalised-health-context

Worldwide eHealth cross-border services

The following worldwide eHealth cross-border services serve as initial steps:

1) Global ePrescription system
2) Global sharing of minimum sets of data (for example, the ISO International Patient Summary) and, progressively, bigger components, such as vaccination passports/summary/e-cards
3) exploring Globally with the EU European EHRxFormat
4) Internationally approved minimum information sets for advanced data-rich medical devices
5) Internationally approved and maintained digital information leaflets for prescribed drugs.
6) International sharing of larges datasets for research/public health based on Commonly agreed minimum sets of data

Global Treaty on Digital Health

32 countries and territories of the **Americas** together

Pan American Health Organization

IDB Inter-American Development Bank


OPS
BID
Legal & Regulatory
Policy
Care Process
Information
Applications & Services
IT Infrastructure
Security, Privacy, Governance
Gazelle
Testing Continuum


BRASIL - ARGENTINA - PANAMA - PERÚ
BOLIVIA - URUGUAY - COLOMBIA
3
LISTADO DE VARIABLES - CONJUNTO MÍNIMO
INDICADORES
DICCIONARIO UNIFICADO Y CODIFICADO
CONECTIVIDAD E INFRAESTRUCTURA
NORMATIVA Y GOBERNANZA
ENFOQUE DE DERECHOS - PROCESOS
VOLUNTAD DE COMPARTIR DATOS - CONSENTIMIENTO
CONTENIDO MÍNIMO DE DATOS A INTERCAMBIAR
TERMINOLOGÍA Y CODIFICACIÓN
UNIVERSALIDAD


Intercambio
Información Inclusiva
Riesgos
Oportunidades


Gobernanza/Cuestiones Jurídicas

G20 Projectathon – December 2022

DDCC (4)	DCC (13)	SMART Health Cards (6)	DIVOC (3)	ICAO (8)	DID (3)
Indonesia	France	Senegal	Indonesia	Australia	ICAO Health Master L (3 systems)
Perou	Netherlands	Canada	Canada	Nauru	European Commission
Uruguay	Uruguay	USA WA State DOH	PathCheck Foundation	Japan	PathCheck Foundation
PathCheck Foundation	Colombia	Puerto Rico		Tuvalu	
	Perou	Japan		Samoa	
	United Arab Emirates	PathCheck Foundation		ICAO -VDS-NC Check (Australia)	
	Italy			PathCheck Foundation	
	Singapore			Canada	
	Paraguay				
	Israël				
	Canada				
	PathCheck Foundation				
	ICAO				

THANK YOU!

Any Questions, comments,
follow up discussions fell free
to email me

Henrique@henriquemartins.eu