



The International Patient Summary Standard and the Extensibility Requirement

The IPS Standard and the Extensibility Requirement

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PHealth 2020

A conference, all about:

‘ubiquitous’, ‘pervasive’, ‘mobile’ computation and computing artefacts applied to the Healthcare domain

Terms particularly appropriate for describing the content of this conference:

- Conjure up exciting innovations and the Welcome includes, but does not exhaust, scientific topics such as:
 - **micro-nano-bio smart systems**
 - **virtual care**
 - **game and gamification**
 - **intelligent and connected health devices**
 - **opportunities and challenges of AI and robots in healthcare**
 - ...

Check my invitation...

are these topics worlds apart from introducing standards and standardization?

Standards appropriate for pHealth?

- Standards are not ‘rocket science’ ...
 - Although, for success, ‘space travel’ is probably dependent upon them!
- In this conference, however, I do not expect, to convince the audience that ‘standards’ are exciting!
 - However, I do hope to convince you that they can be relevant!
- The descriptive terms for pHealth i.e., ‘ubiquitous’, ‘pervasive’, ‘mobile’, can also be directly applied to the humble **Patient Summary**, and the creation of a sustainable international standard, **the IPS**

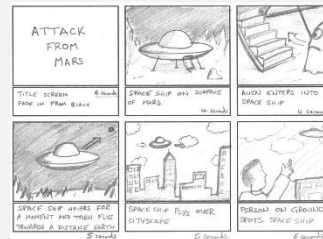
The IPS Standard & the Extensibility Requirement



What is it ?



The
Stakeholders



The Story

THE SUBSTANCE...

What the IPS is ?

■ International

It emphasizes the need to provide generic solutions for global application beyond a particular region or country.

- Patient
- Summary

Health record extract comprising a standardized collection of clinical and contextual information (retrospective, concurrent, prospective) that provides a **snapshot in time of a subject of care's health information and healthcare**

SOURCE: ISO/TR 12773-1:2009 (en) Business requirements for health summary records — Part 1: Requirements]

The IPS: a focused PS



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



It is **minimal and non-exhaustive**



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

The IPS: a focused PS



Designed to be **simple**

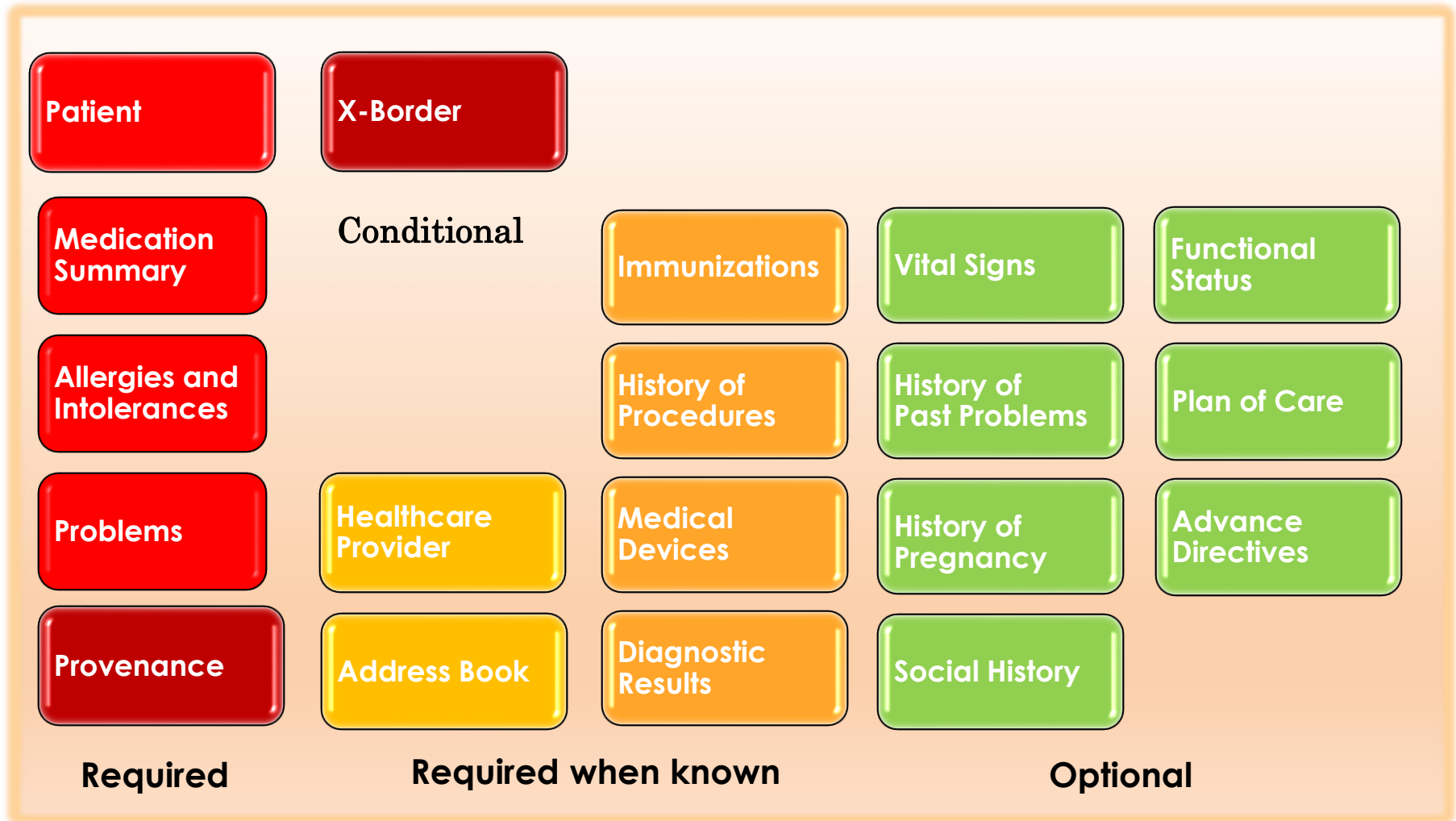


Usable **any time**, in **any place**; by **any one**



Multi-beneficiaries: Individuals, Healthcare Providers, Society

Macro IPS Data Blocks



The PS means what? To who...

- The concept of a **Patient Summary** (PS) is not new; arguably, it has been in existence since clinical record keeping began
- Ubiquitous, the PS is part of the fabric of healthcare
- Everyone seems to have their
 - own idea about what it is, and
 - what it should do
- The PS is simple in concept ...
- But the PS come with its own baggage



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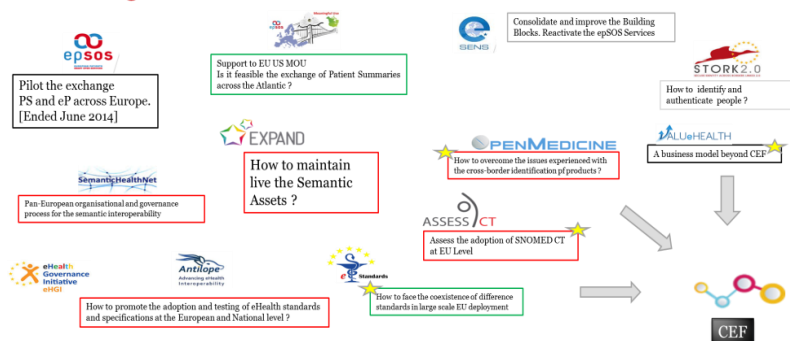


**The IPS....is
not a flower
in a
desert...**

THE STAKEHOLDERS...

The more recent part of a long history ..

Moving to the CEF.....



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

JASEHN
Joint Action to Support the eHealth Network

GUIDELINE
on
the electronic exchange of health data under
Cross-Border Directive 2011/24/EU

Release 2

Patient Summary for unscheduled care

Document Information	
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Approved by JASEHN affEC	The
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Document Number	20.3.1
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eHealth Network Guidelines 2013-2016, 2020



Transatlantic eHealth/Health IT Cooperation Roadmap

July 2016



Structure of Roadmap

This main Roadmap document sets out the vision, the main challenges, the scope and descriptions of each of the work-streams. The Roadmap Annex contains the specific actions and outcomes/deliverables with their corresponding milestones and due dates for each work-stream. The Annex (which will cover a 12 to 18 month timeframe) will be regularly updated to keep stakeholders fully informed of progress. The Roadmap activities overall will cover a longer period.

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: enforcement of the IPS concept.



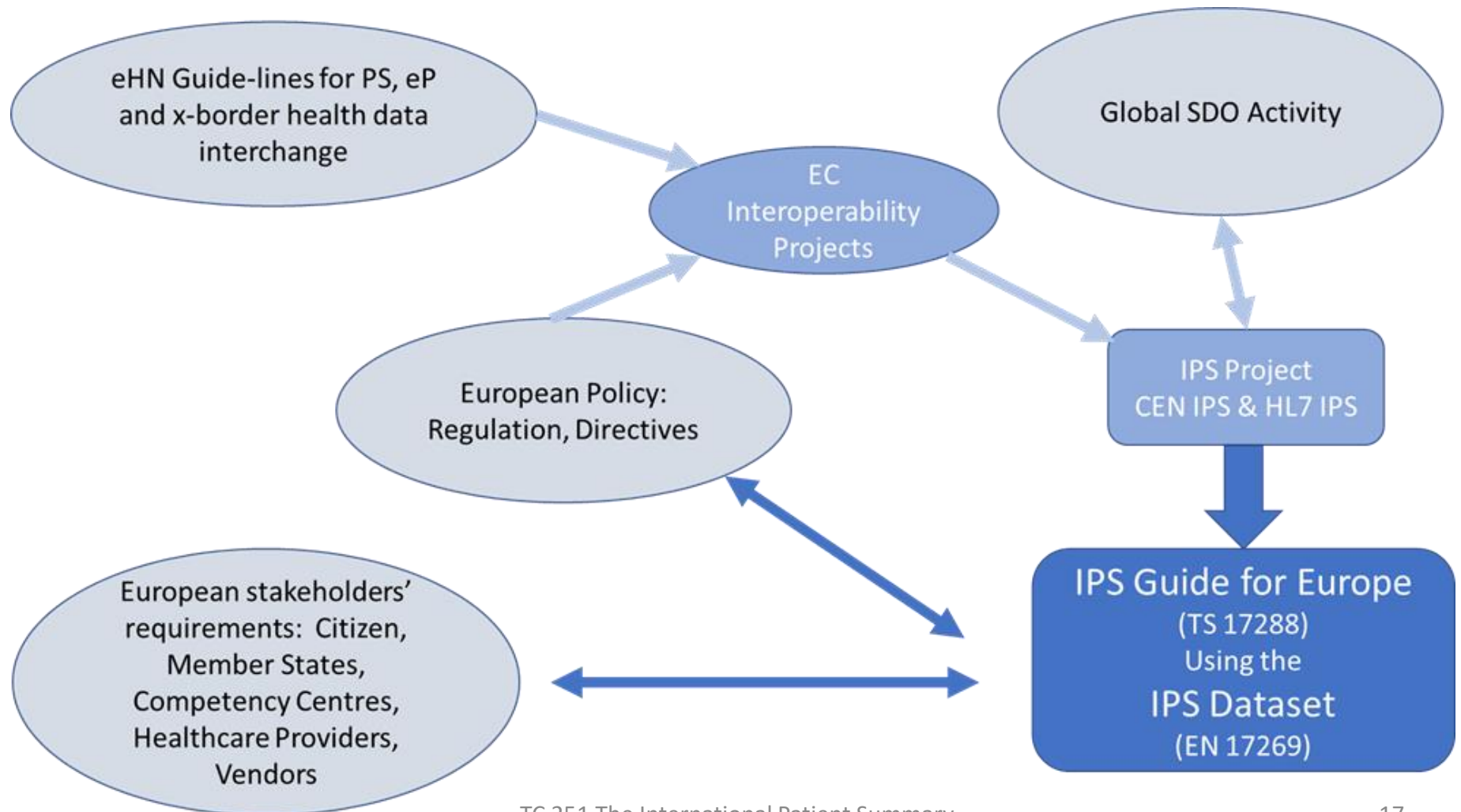
CEN IPS and Stakeholders

- CEN/ TC251 was unable to contribute effectively to PS activity outside of Europe ...
- Contract awarded to CEN/ TC 251 from EC
 - Required tasks:
 1. Participate globally, particularly with HL7
 2. Formalise the PS dataset in the eHN Guidelines
 3. Deliver (1): An International PS standard
 4. Deliver (2): An Implementation Guide for Europe
 5. Socialise outputs to wider stakeholder community



.. it has not been built on a green field...

Stakeholder Influences



The IPS Use Case, 4 Scenarios, and the Subject of Care

- Original use case was to exchange a Patient Summary cross-border for unscheduled care
- User requirements suggested this was just one scenario of a broader use case to deliver a PS at the point of care. The Scope was extended:
 - **IPS Scenario 1: Cross-Border, Unscheduled care**
 - **IPS Scenario 2: Local, Unscheduled care**
 - **IPS Scenario 3: Cross-border, Scheduled care**
 - **IPS Scenario 4: Local, Scheduled care**

Stakeholder Awareness

CONTRIBUTE TO Global Collaboration

in the context of

JIC Standards Set
for Patient
Summary

HL7 IPS (AKA.
INTERPAS)

EU/US
Memorandum of
Understanding

COORDINATE European Standardisation

taking into account

eHN guidelines
and their revision

eHealth Digital
Services
Infrastructure

EC eHealth
Projects

ENGAGE WITH Local Implementation

reaching out to

Patient Summary
implementation
and testing

National Contact
Point for eHealth

National
Competency
Centre for eHealth



**SDOs do not come
from mars...**

- SDO are communities
- Contain a mixture of academic, commercial, governmental, HC providers, researchers, and regulators

The IPS Standard normalizes the dataset provided by the European Guideline on cross-border exchange of a patient summary.

Network of interested parties (including the EC, and 27 European countries comprising ministries and competency centres; policy-driven in Europe) and other stakeholders from across the world.

SDO's not always stakeholder friendly and may appear alien, yet

The eHN Dataset was an obvious candidate for standardization:

The dataset is described as being both 'minimal and non-exhaustive', which required extensibility to be addressed.

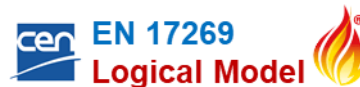
THE STORY...



CEN EN 17269:2019

Immunizations Content Status	C	Coded Element
Immunizations list	C	List
Immunization	R	Label Concept
Vaccine for type of disease	R	Coded Element
Target disease list	O	List
Target disease	R	Coded Element
Date of immunization	R	Date Time
Product administered	O	Label concept
Brand name	RK	Text
Product Administration Process	O	Label concept
Performer	O	Healthcare Provider
Route of administration	O	Coded Element

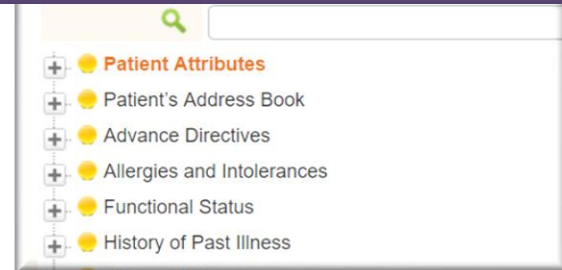
- Minimal
- Non-exhaustive
- Specialty-agnostic
- Condition-independent



Concepts CEN/TC 251 prEN 17269

Datasets

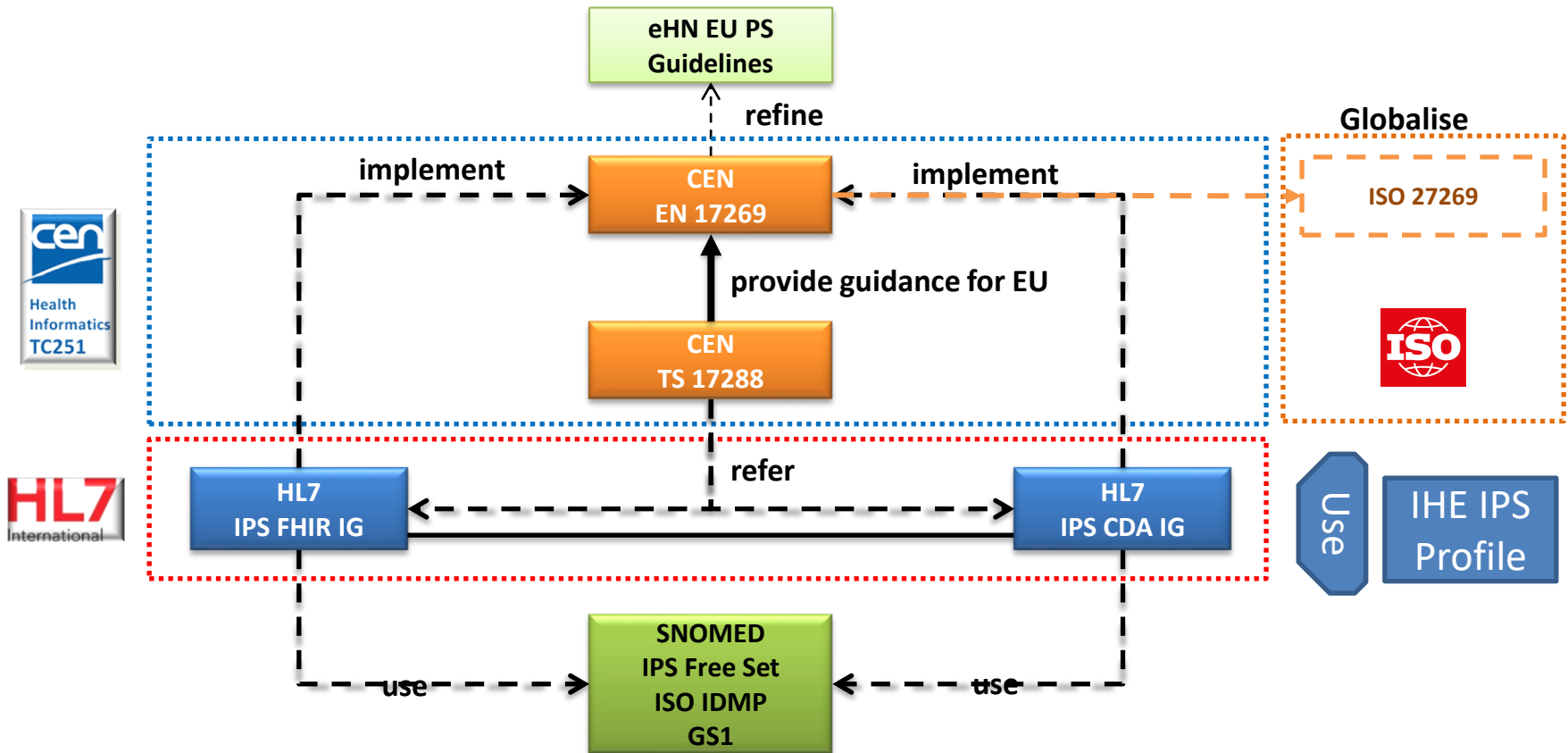
<https://art-decor.org/art-decor/decor-datasets--hl7ips->



Name	Type	Description & Constraints
ImmunizationsSection	Section	Immunizations Section br-imm-1: If content status positive then immunization list SHALL be non-empty AND the content status SHALL be omitted.
ContentStatus	CodedElement	
Immunizations	List	
Immunization	Immunization	

Name	Type	Description & Constraints
Immunization	LabelConcept	Immunization
Type	CodedElement	Vaccine for type of disease
TargetDiseases	List	Target diseases
TargetDisease	CodedElement	Target disease
DateOfImmunization	DateTime	Date of immunization
ProductAdministered	LabelConcept	Product administered
BrandName	Text	Brand name
ProductAdministrationProcess	LabelConcept	Product administration process
Performer	HealthcareProvider	Performer
RouteOfAdministration	CodedElement	Route of administration

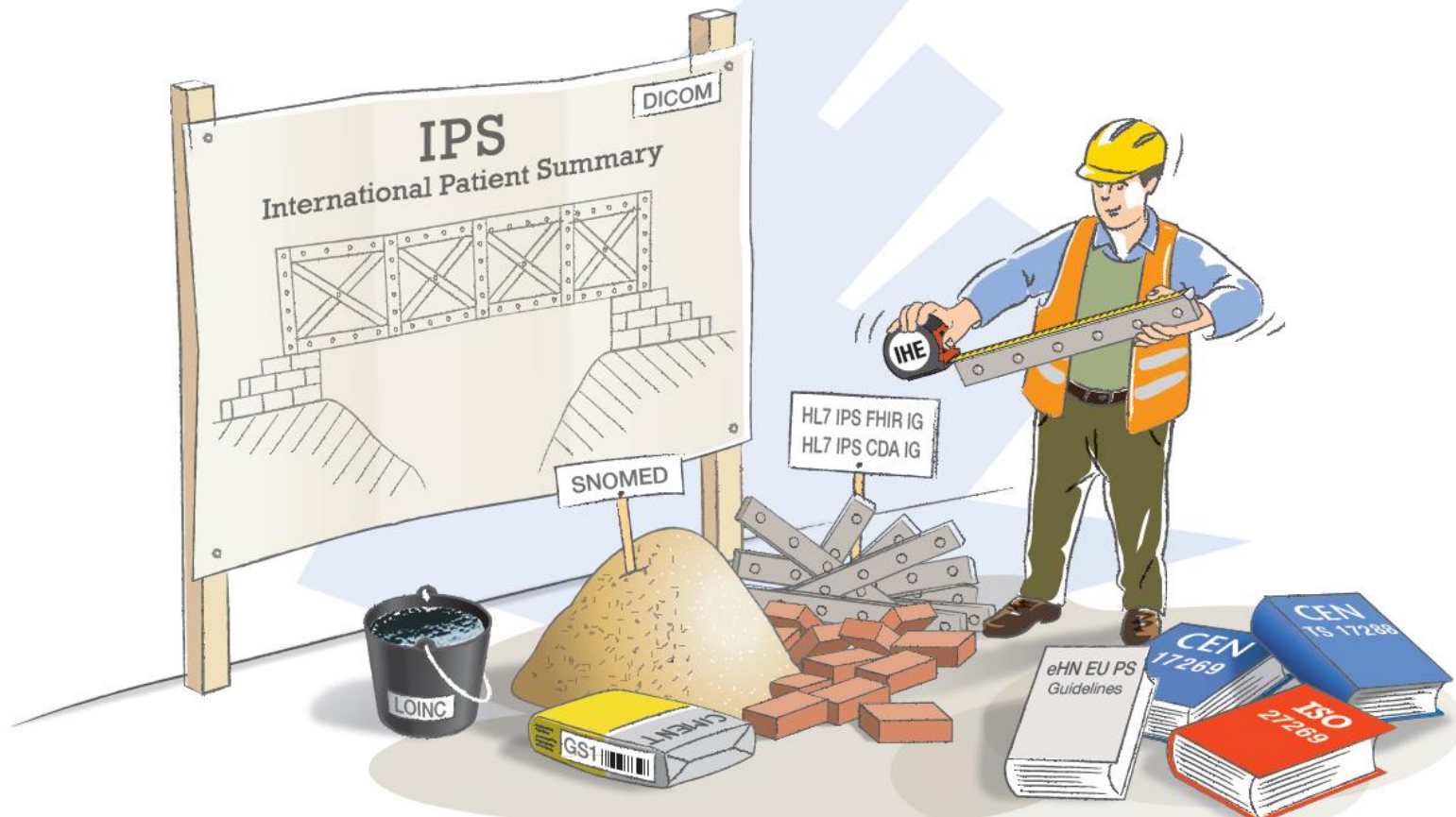
The IPS project Products



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

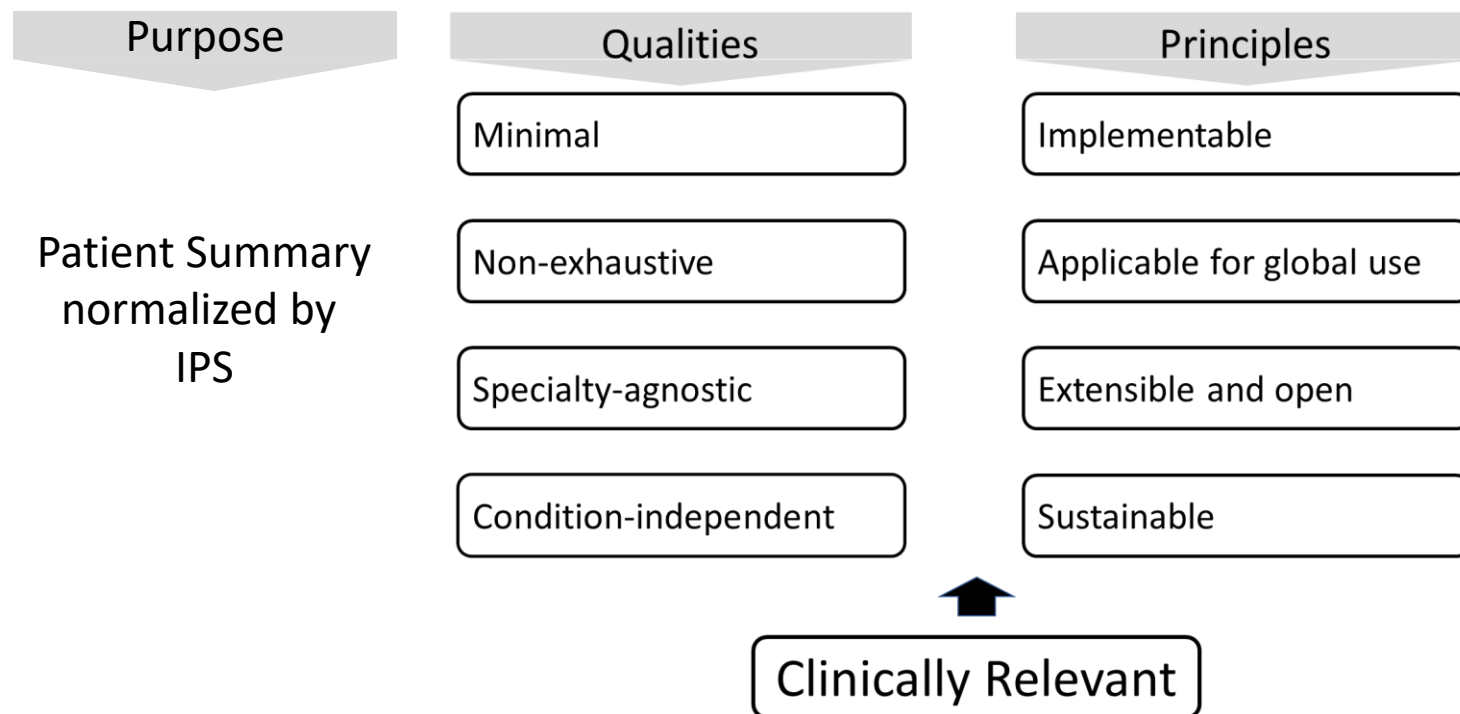
IPS FHIR IG: how to implement the IPS using HL7 FHIR
IPS CDA IG : how to implement the IPS using HL7 CDA

More SDO involvement and stakeholder interest is welcome, but necessitates clean governance particularly managing extensibility



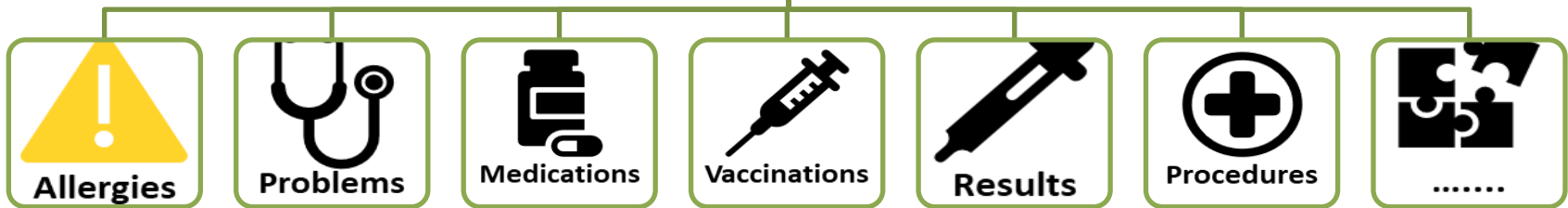
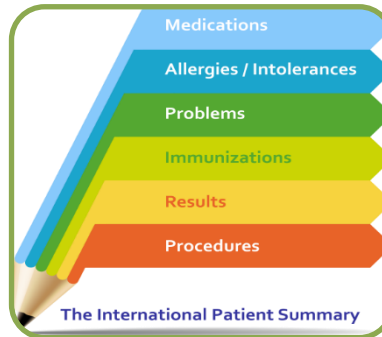
Patient Summary as an identifiable dataset

“essential and understandable”



The IPS Approach

It uses a document Metaphor !

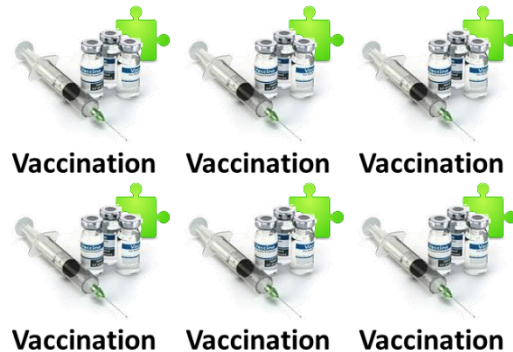


...composed by a set of reusable data blocks !

The IPS “library”



 extensions



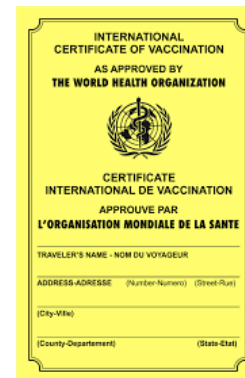
**Library of
reusable..**

(fragments;
resources; building
blocks;...)

Common “core” set of data

With minimal common
terminologies

Extensible



The IPS “library”

Trillium II

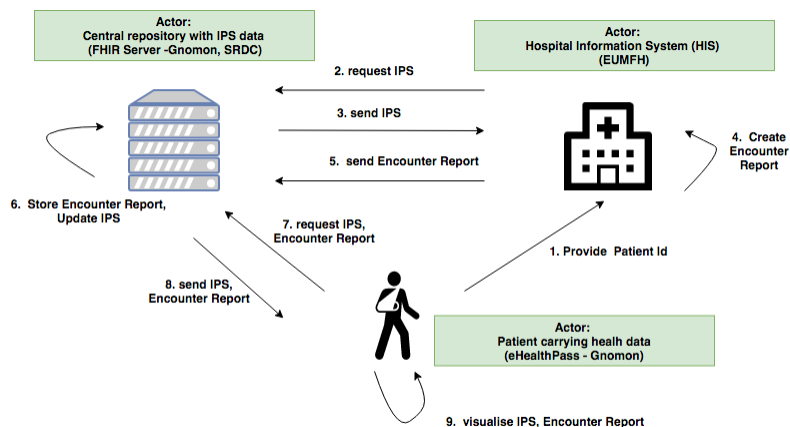
Reinforcing the Bridges and Scaling up
EU/US Cooperation on Patient Summary



EU ModEx, Bucharest, 2018 Oct 15-17



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



Why extend the IPS?

Examples include:

- Stakeholder requirements and acceptance:
 - technical developments and feedback from users
- The IPS Dataset is a starter set; it is not yet comprehensive:
 - The IPS is meant to be understandable to all clinicians, but the core should be defined by clinical consensus.
- Clinical knowledge is dynamic and what is core will also be challenged over time.
- New requirements, such as COVID-19

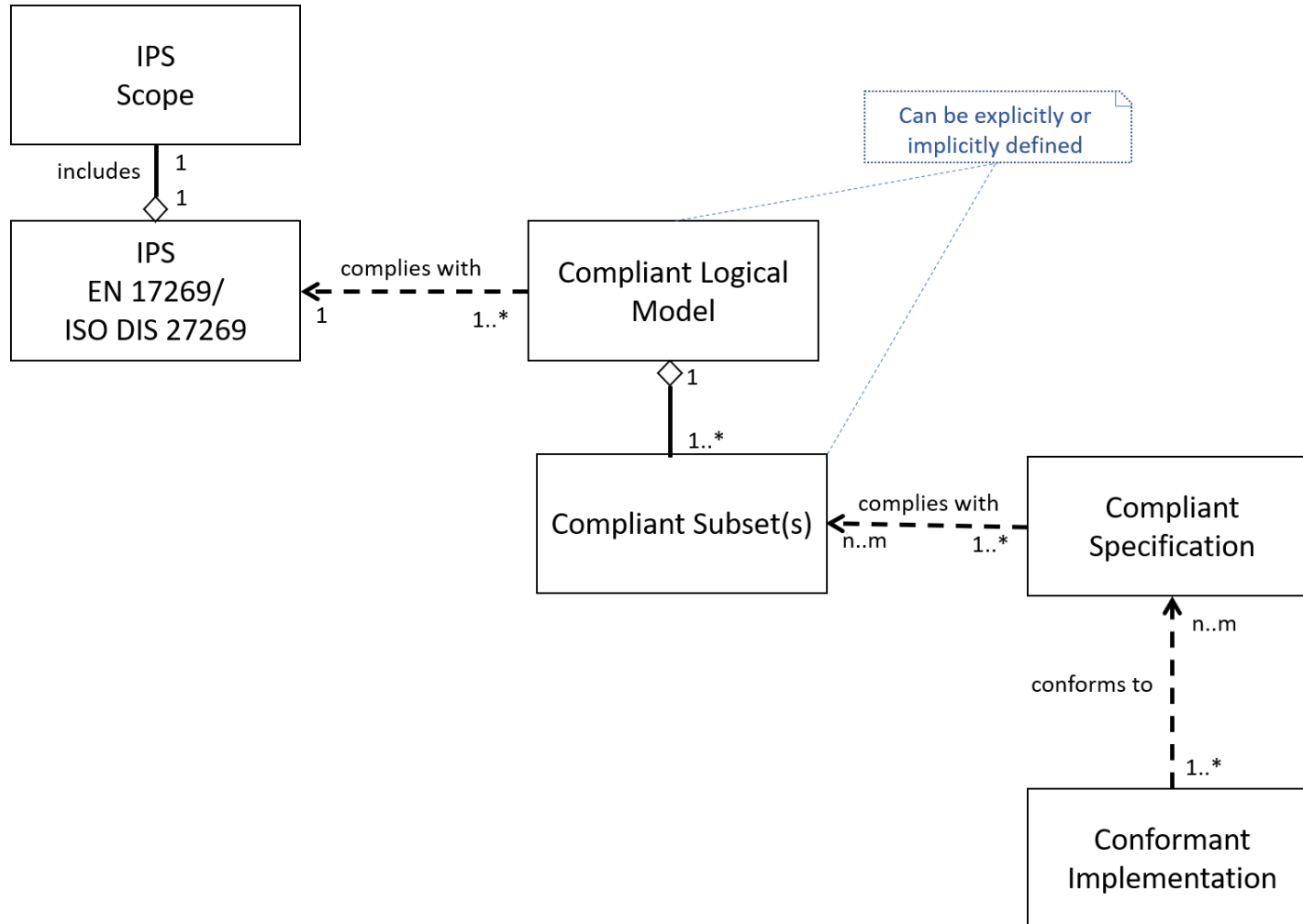
Extensibility

There are two broad, yet distinct ways of extending the use of the IPS:

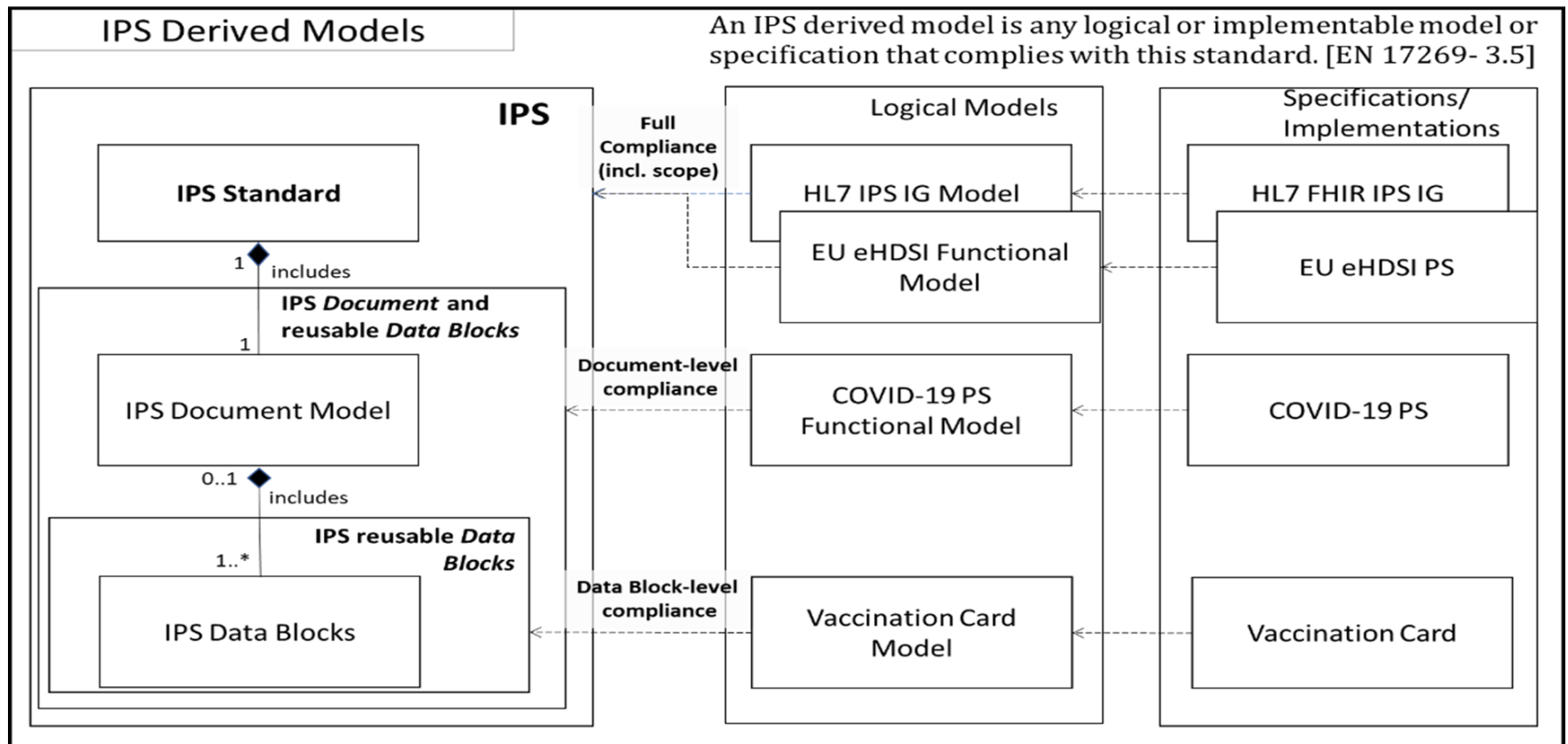
- Refining, complementing and profiling the IPS Data Set for different health conditions and applications that relate to model derivation of IPS from the current standard, (e.g. Vaccination card, and COVID-19). Profiling also enables the IPS data blocks to be used in Computable Clinical Guidelines (CCG).
- Evolving the base or foundational IPS standard by consensus and that will require that the IPS standard be updated by new clinical and technical requirements from use (e.g. the vulnerable Subject of Care, and COVID-19).

The first needs to be brought back to the IPS Reference model. From the IPS reference model it is possible to derive a number of compliant logical models that constrain it, and these lead to implementable specifications, such as the HL7 CDA Implementation Guide, the HL7 FHIR IPS IG, and the IHE IPS profile

Conformant implementations to the IPS Reference Model



Three levels of compliance



COVID-19 Example showing document level compliance

- COVID-19 is unlikely to be the last pandemic ...
- **Today**, Stakeholders are looking for a kind of ‘COVID-19 immune flag’ to be highlighted in the IPS.

Three associated facts necessary to record in the patient summary seem to be immediately available in the present IPS:

I have / had this disease...	[IPS Sections: Problems / Past problems]
tests say that ...	[IPS Section: Results]
I've been vaccinated against ...	[IPS Section: Immunization (not applicable for COVID-19 yet)]

Flexible IPS provides Options

- The 'flag' could be indirectly derived from the existing standard. This puts the onus on the user interface rather than the IPS Data Set. It also semantically overloads the already overloaded 'Problem' IPS Sections.
- Creating a new Public Health/ pandemic IPS Section is another option, although it may stretch the idea of the IPS being for an individual subject of care, but this could still relate to the Immunization Section.
- Yet another option is to consider the attribute collection for Patients and to consider 'immunity' to be an aspect of a person's health state, perceived or recorded as a health matter; conversely 'lack of immunity' could be recorded as a specialization of 'problem'.

Current solution under test

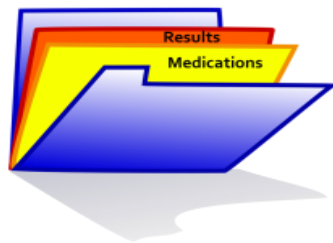
- The solution suggested for the time-being is to retain the scope of the Immunizations IPS Section to the vaccination-driven approach but allow for optional immunity data.
- In practice the conformant implementations will address the immediate need and the governance processes will ensure the reference model is updated.

A low-angle, close-up shot of a person's legs walking on a wooden deck. The person is wearing blue denim jeans and white sneakers with brown laces. The background is a blurred wooden deck, suggesting movement. The text "...this is just the first step..." is overlaid in the center in a white, serif font.

...this is just the first
step...

The IPS product family

The IPS standards



The «IPS»

document



The IPS data blocks

library

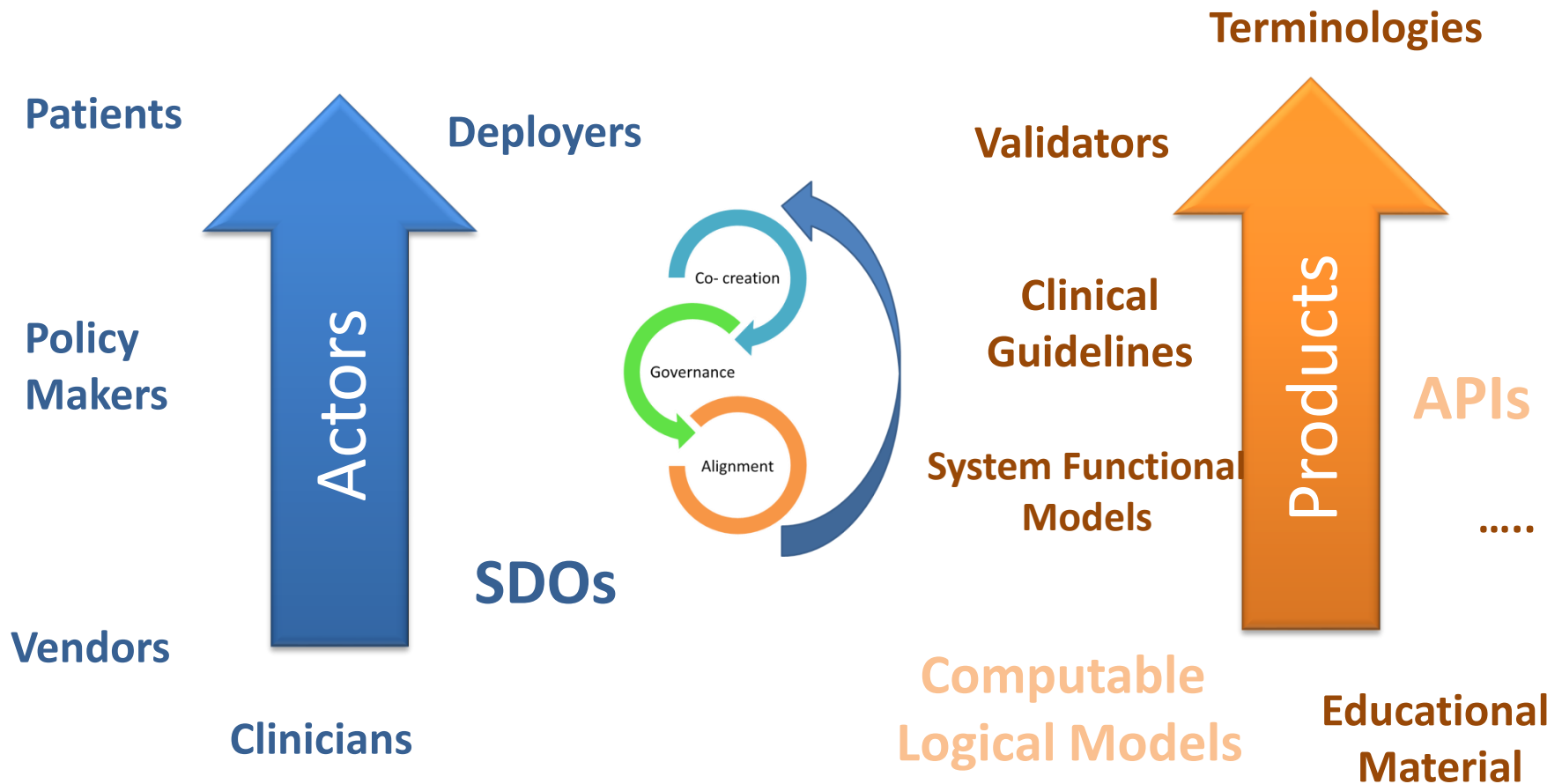
Good candidate support for the E-EHR-XF !

The IPS as ISO standard

- The **EN17269** (IPS data set) is moving to ISO.
- June 2020: Fast-Track Process approved
- September 2020: Final Draft Ballot resolution closes on the 23rd September.
- The resulting Standard ISO 27269 will be published in 2021



Towards an «IPS ecosystem»





PS

International Patient Summary

<http://bit.ly/IPS-Story>

Stephen Kay