

How the International Patient Summary Standard can contribute to the treatment of a Rare Disease



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X-eHealth and RD-Code workshop
(November 2021)

Overview of presentation

- ❑ The question ... (i.e., How can the IPS contribute to the treatment of a RD)
 - ❑ Use the given story of a Rare Disease Sufferer
 - ❑ With roles!
 - ❑ Present the worst case and better case scenarios
 - ❑ Defining the IPS ... “Essential” & “Understandable”
 - ❑ Introduce the non-exhaustive core IPS Datablocks
 - ❑ Implementation-independence & specialty-agnostic w.r.t. RD
 - ❑ A non-clinician’s suggestions to improve the relevance of IPS for RD
 - ❑ Breadth with respect to the IPS Datablocks
 - ❑ Depth with respect to the IPS Datablocks
 - ❑ IPS Conformance and 3 levels of compliance
 - ❑ The IPS and the EHR
- ❑ The answer ...

A short story of a Rare Disease Sufferer

[Narrator]

A 15 years-old Czech boy suffering from **juvenile** Steinert disease is on holiday in Barcelona, Spain. {On his own or with parent?}

After the boy's flight, he starts coughing and is progressively short of breath.

Finally, after a couple of days of suffering, he goes to the hospital emergency department

[Patient]

"I have had a cold for a few days and

I am short of breath,

I also have disabling abdominal pain.

I have been diagnosed with Steinert disease and I frequently have difficulty breathing"

Worst case scenario

[Attending clinician]

- “I do not know this boy
- I only know about the problem from the boy, {dependent on language translation, memory, his understanding and his ability to communicate, and trust.}
- He says he has Steinert disease, but I do not know much [probably nothing?] about Steinert disease, {how much time do I have to do a search/lookup for more specialist information?}
- but I want to rule out [performing] a surgical abdomen [procedure] {Information about procedure may inform my action}”

[Narrator]

“Patient makes a respiratory arrest when laying down for examination. Intubation is difficult and a tracheotomy is performed.”

Better Scenario

[Narrator] reports that Patient Summary is available:

- {Spanish doctor requests legitimate access to boy's PS, which is then generated out of the Czech EHR.}
- IPS Medical Alert in IPS indicates difficult to recognize 'Juvenile' form of Steinert disease and notes too a possible risk that the patient may have behavioral problems...

[Attending clinician]

- "I do not know much about Steinert disease, {contact specialist...}
- I can access patient history and alert messages {historic and current problems}
- I can see the links to emergency guidelines published in Orphanet in Spanish, to avoid further complications for the boy [specialist link, CPGs, Procedures ...].
- I can also call the boy's [preferred] doctor at his hospital in Prague. {Address book}
- If time, I might set up a juvenile Steinert emergency teleconsultation group. In this session, getting additional data from the hospital admission such as labs and images [outside of PS, an extended encounter]".

What the IPS is ?

■ International

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

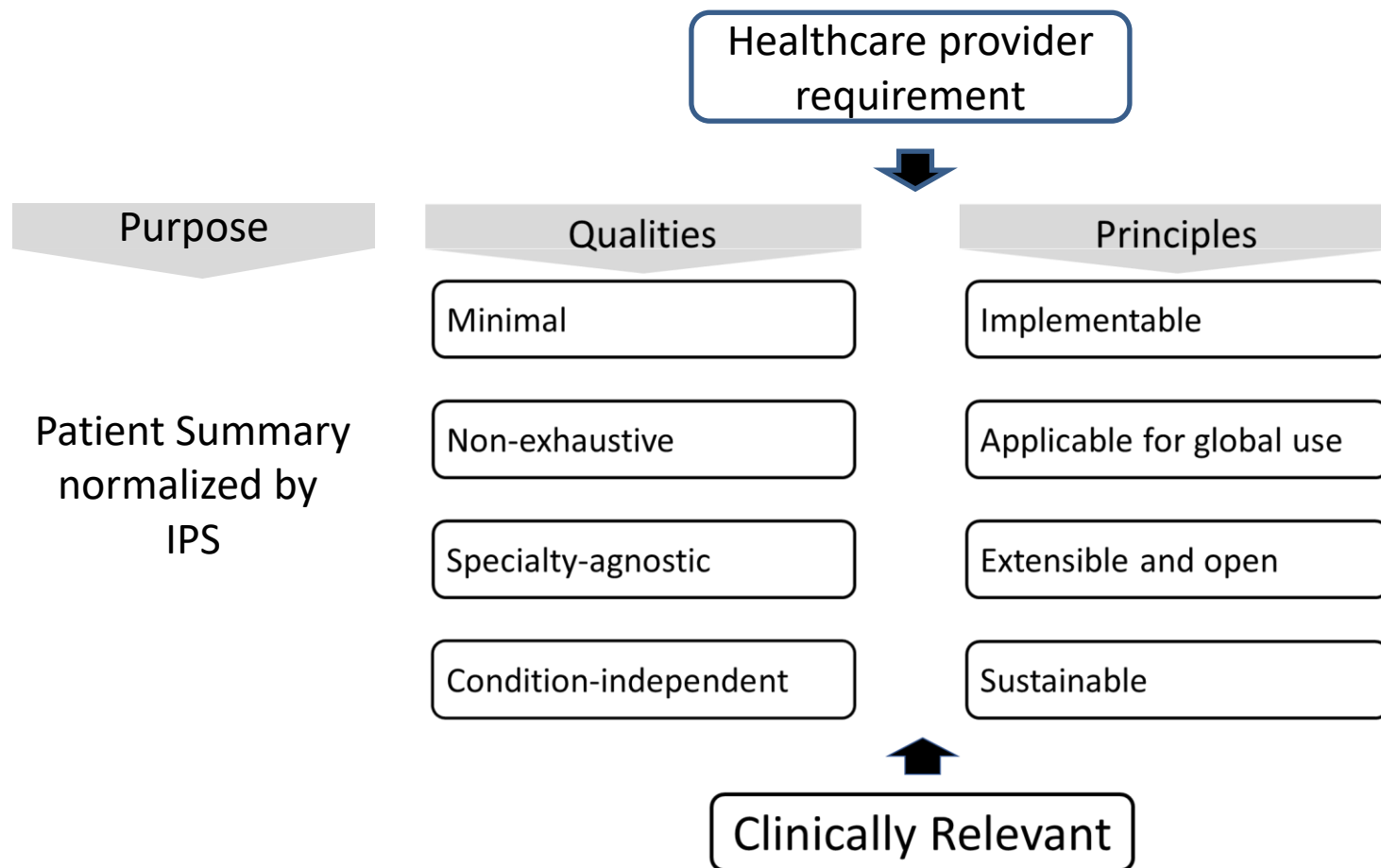
- Patient
- Summary

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]

Patient Summary as an identifiable dataset

“essential and understandable”



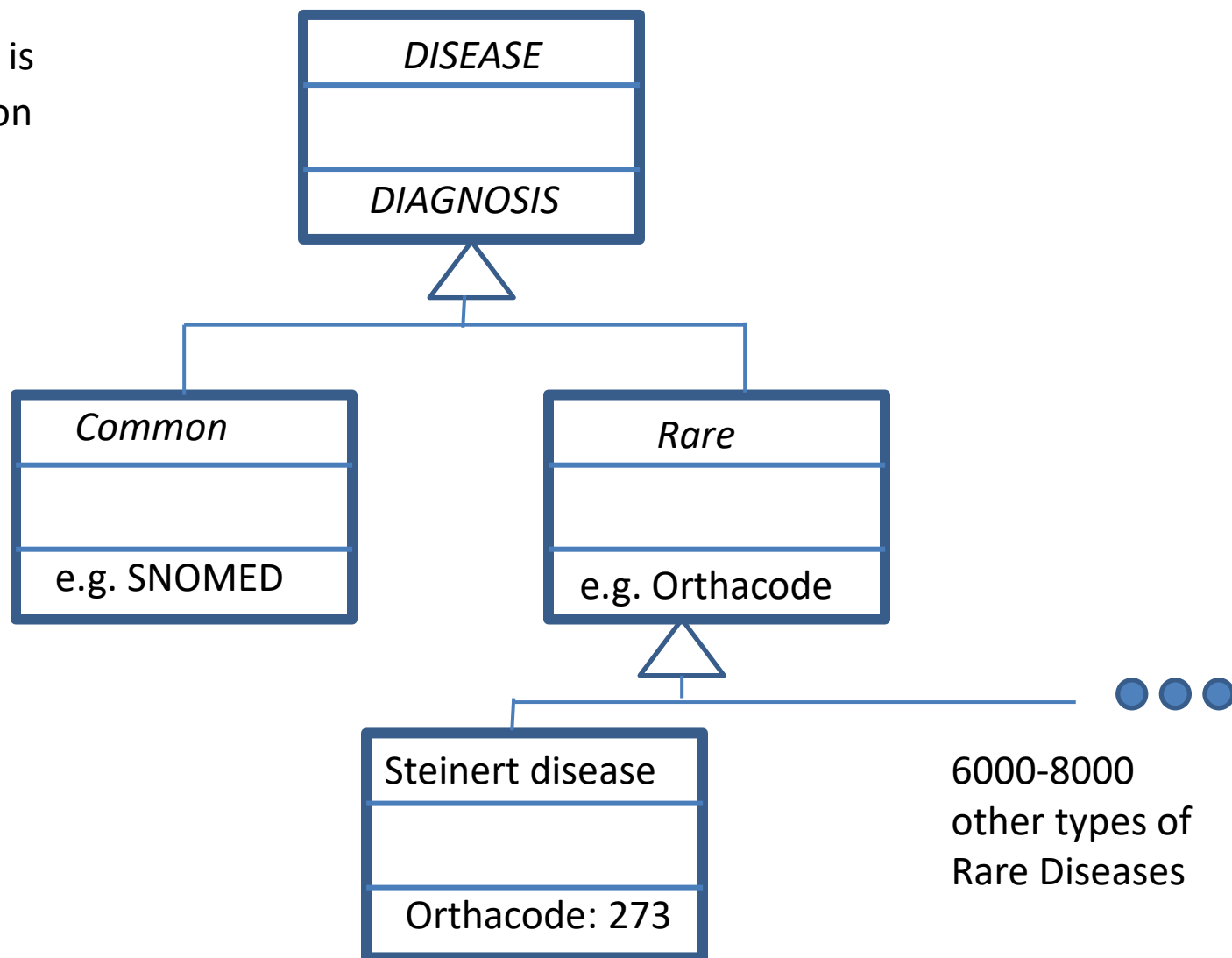
IPS Core Dataset – Not Exhaustive

Patient attributes	Allergies & intolerances	Problems incl. diagnosis	Medication summary	Immunization (incl. Vaccinations)	Results	Vital signs
Healthcare provider	History of procedures	History of past illness/problems	History of Pregnancy	Medical Devices (incl. implants)	Functional status	Social history (incl. life style factors)
Address-book	Advance directives (i.e., living wills)	Care plan				
Provenance						
Cross-border (conditional)						

Breadth and Depth
can (and will) be added,
as the use of data adds
clinical value.

IPS quality: Specialty-agnostic

➤ *IPS* standard is
implementation
-independent



IPS Datablocks for Rare Disease

(SK's suggestions, breadth)

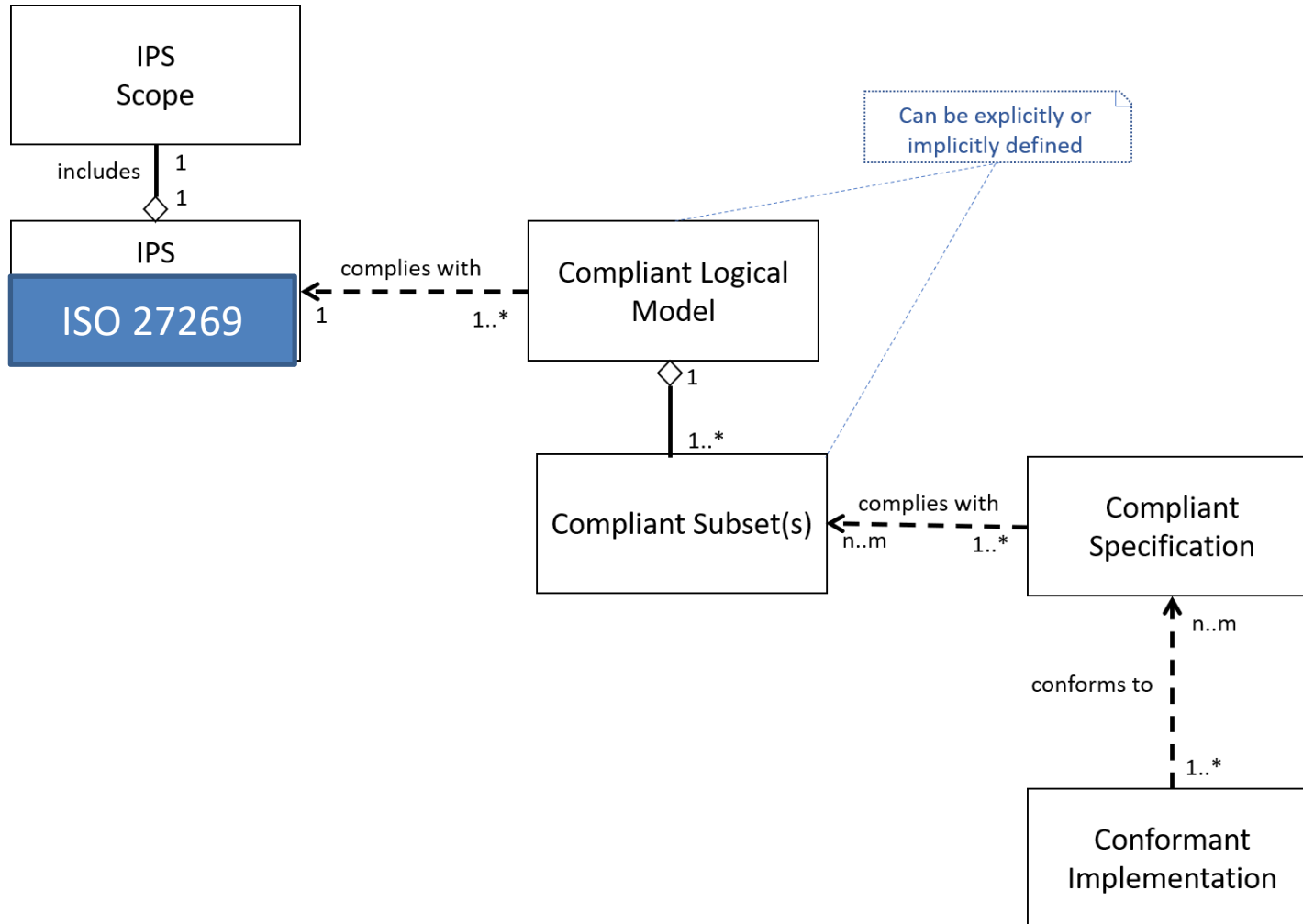
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Address-book	Advance directives (i.e., living wills)	Care plan				
Provenance			Alerts (incl. Risks)	Child-health	Family history	Genetic details
Cross-border (conditional)				Recent Encounters	Computable Clinical Guidelines	Patient Story

IPS Datablocks for Rare Disease

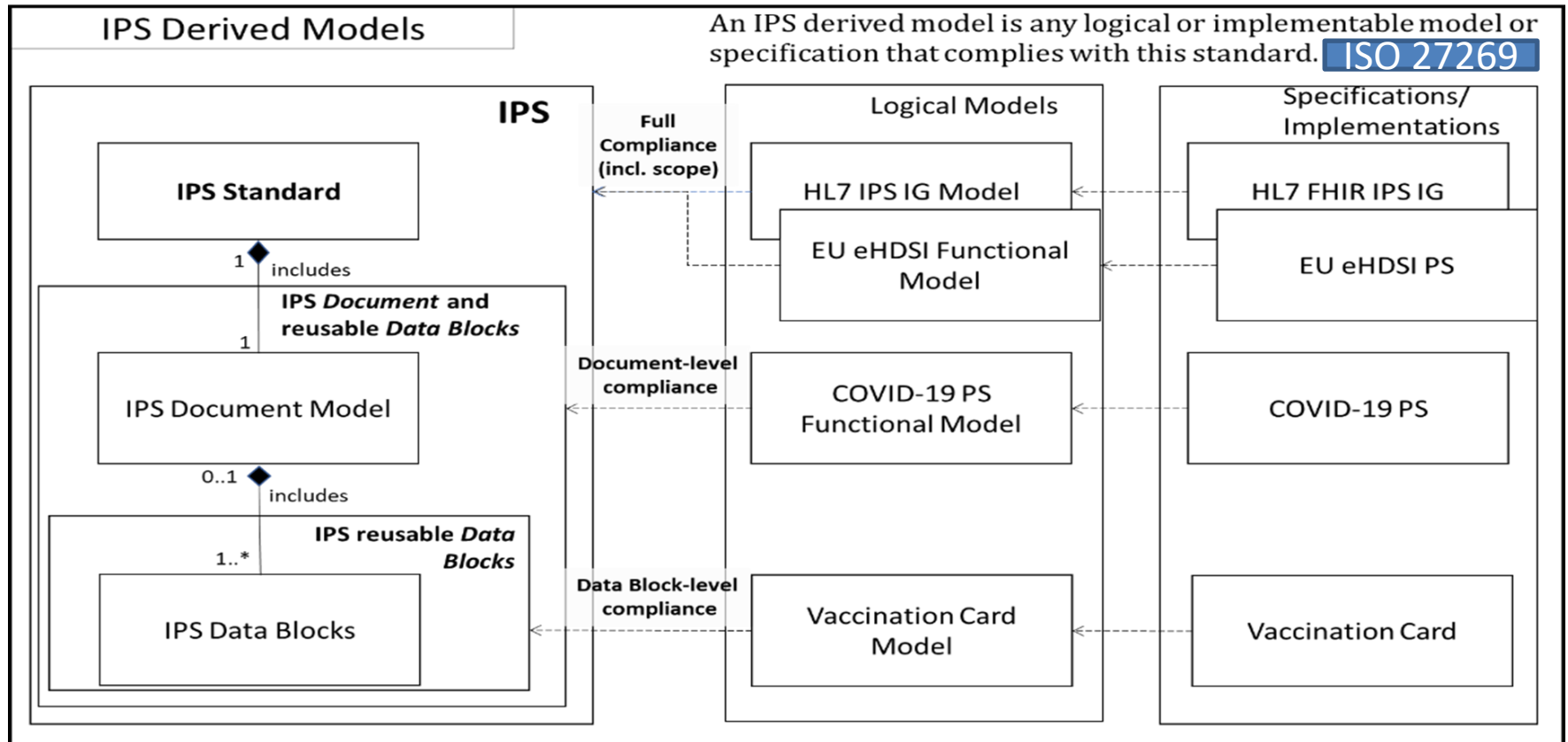
(SK's suggestions, breadth and depth)

Patient attributes	Allergies & intolerances	Problems incl. diagnosis	Medication summary	Immunization (incl. Vaccinations)	Results	Vital signs
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Address-book	Advance directives (i.e., living wills)	Care plan				
Provenance			Alerts (incl. Risks)	Child-health	Family history (incl. Genetics)	
Cross-border (conditional)				Recent Encounters	Computable Clinical Guidelines	Patient Story

Conformant implementations to the IPS Reference Model



Three levels of compliance



The IPS and the EHR

- The EHR is one source, perhaps the only source, for producing a summary. A summary is essentially a derivative.
- In planned care, why not always use the full EHR?
 - If IPS needed another reason for existing, it would surely be that it has the potential to mitigate the burden on the clinician by trying to assimilate a full EHR.
 - The IPS can function as a summary board for a record
- Although the IPS is responsible for extensions are not intended to create a full EHR.
- The IPS fulfils a fundamental purpose to an EHR.
- **ANSWER:** YES, but:
 - if the data is not in the source(s), it cannot be in the IPS!



Thank you for listening

9th December 2021 – Free Open Forum on *IPS* –

The Joint Initiative Council in coordination with the Global Digital Health Partnership.

Download the agenda => [Here!](#)

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The new *IPS* website will be launched.