The use of the Patient Summary

Athens Digital Health Week 2025

Capacity Building / Education Track

Dr Robert A. Stegwee

ePatient Dave

Agenda

- The Patient Summary – what is it?
- The Patient Summary – how to use it?
- The Patient Summary – its clinical value
- The Patient Summary – a set of standards

The Patient Summary – what is it?

Some relevant (conceptual) terms

- Electronic Health Record
  - Person/patient Centered
  - Longitudinal
  - Comprehensive
  - Life-long
- Electronic Health Record System
  - Limited to a (group of) provider organisations and/or professionals
  - Maintains a limited portion of the Electronic Health Record
- Personal Health Record System
  - Patient (or representative) is controller of the data
  - Healthcare provider EHR data may be included

The Patient Summary

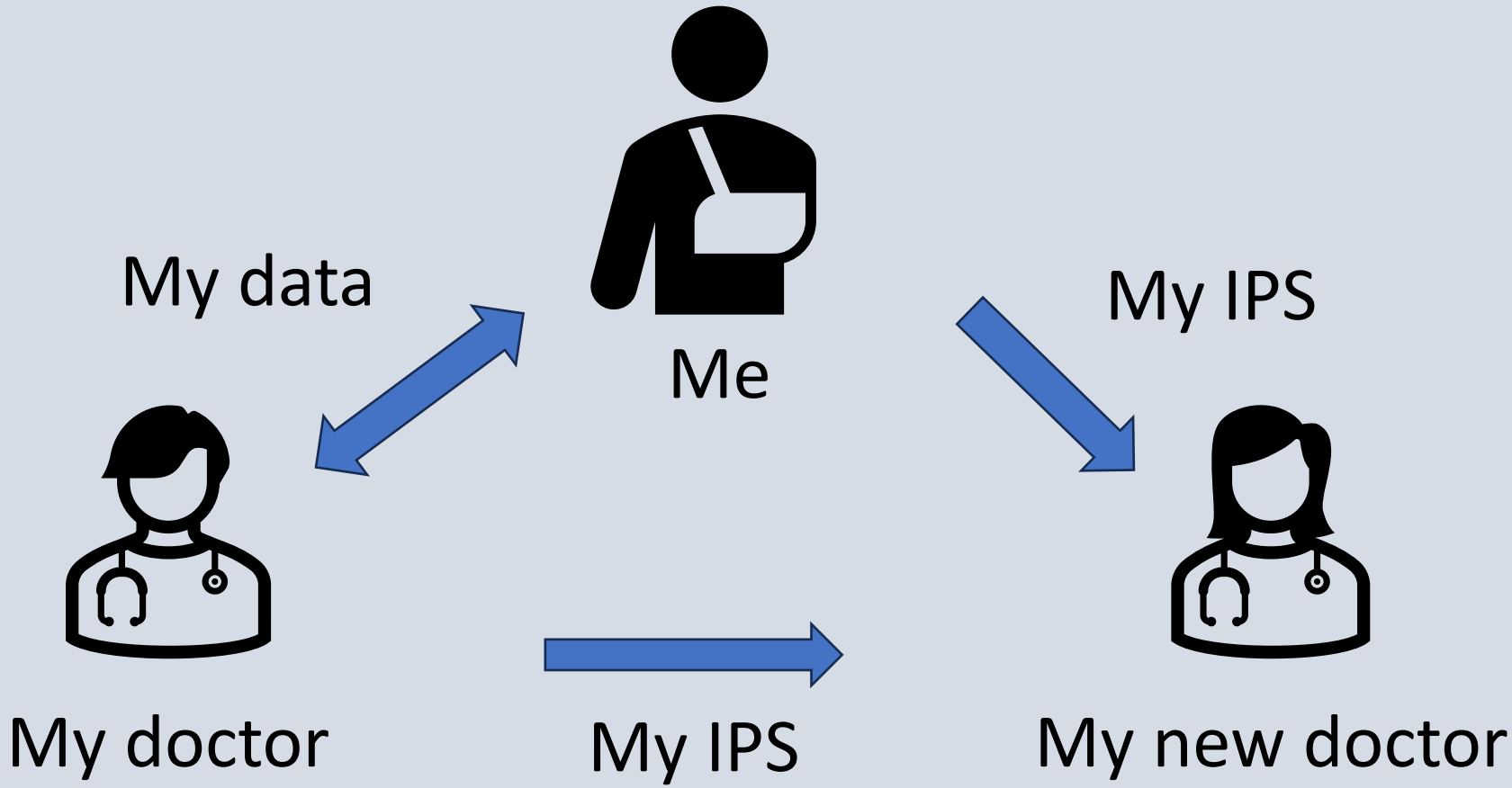
What it is …

- minimal dataset
- basic clinical data
- patient specific
- specialty agnostic
- condition independent
- readily usable
- by all clinicians
- for the delivery of care

What it is not …

- exhaustive dataset
- extensive clinical data
- aggregated across patients
- specialty specific
- condition dependent
- for further processing
- by specific clinicians
- for secondary purposes

Supporting communication in care



New doctor: What can you tell me?

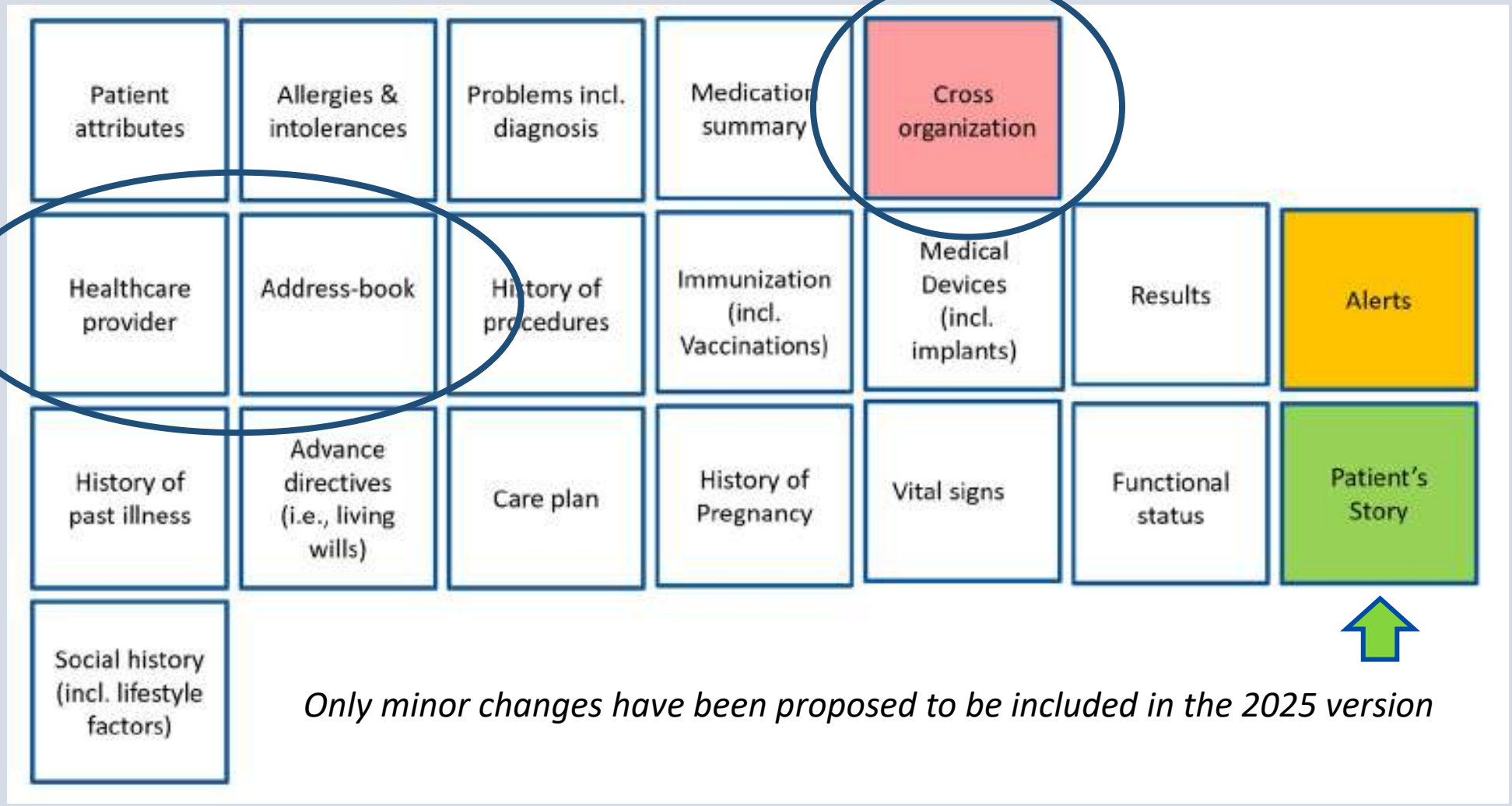
- Patient details (name, date-of-birth, identifiers)
- Problems (type, description, diagnosis, onset date)
- Medication list (product, strength, doseform, instructions)
- Allergies and Intolerances (reaction, agent, severity)

- *These are all current patient data, coded as much as available, but also with narrative text to be readily usable by all clinicians*
- *If you don't know, please DO tell me you don't, otherwise I might assume there are none (problems, medications, allergies)*

I'll give you a summary

- And I even might add
  - Vital signs
  - Advance directives
  - Functional status
  - Medical devices
  - History of pregnancy
  - History of past problems
  - Social history
  - Plan of care

We've identified 20 macro datablocks



Only minor changes have been proposed to be included in the 2025 version

What you put in there is well described

- Definitions, examples, and structure up to five levels deep

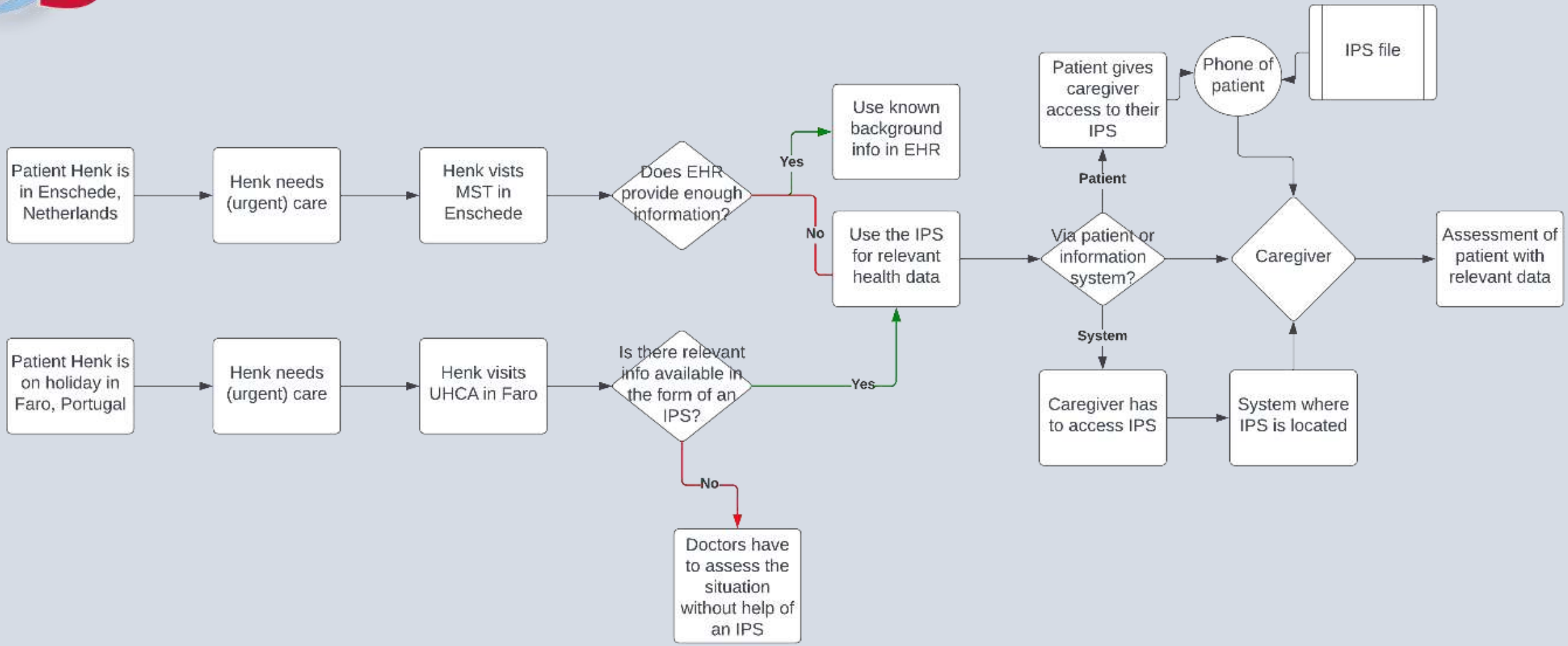
- Of course, it is a best effort to create a patient summary:
  - My doctor can do it for me, based on what health data she has
    - The Electronic Health Record system might be very helpful
  - I can do it myself, based on the health data I have access to
    - A Personal Health Record system might be very helpful
  - An application can automatically create one, based on the data it has access to
    - In FHIR the Patient resource has a $summary operation that does exacly that!

The Patient Summary – how to use it?

Having the information doesn’t help

- The story of the medication list in the referral letter
- **Using the information is the only way it will help you**
- What does that mean???
  - In terms of access to information
  - In terms of processing of information
  - In terms of embedding it in your daily routines

An example process flow



Key elements of process design

How much can be done in preparation of the healthcare professional actually seeing the patient?

How much can be done within the regular digital work environment of both professionals and support staff?

How much can the patient do themselves?

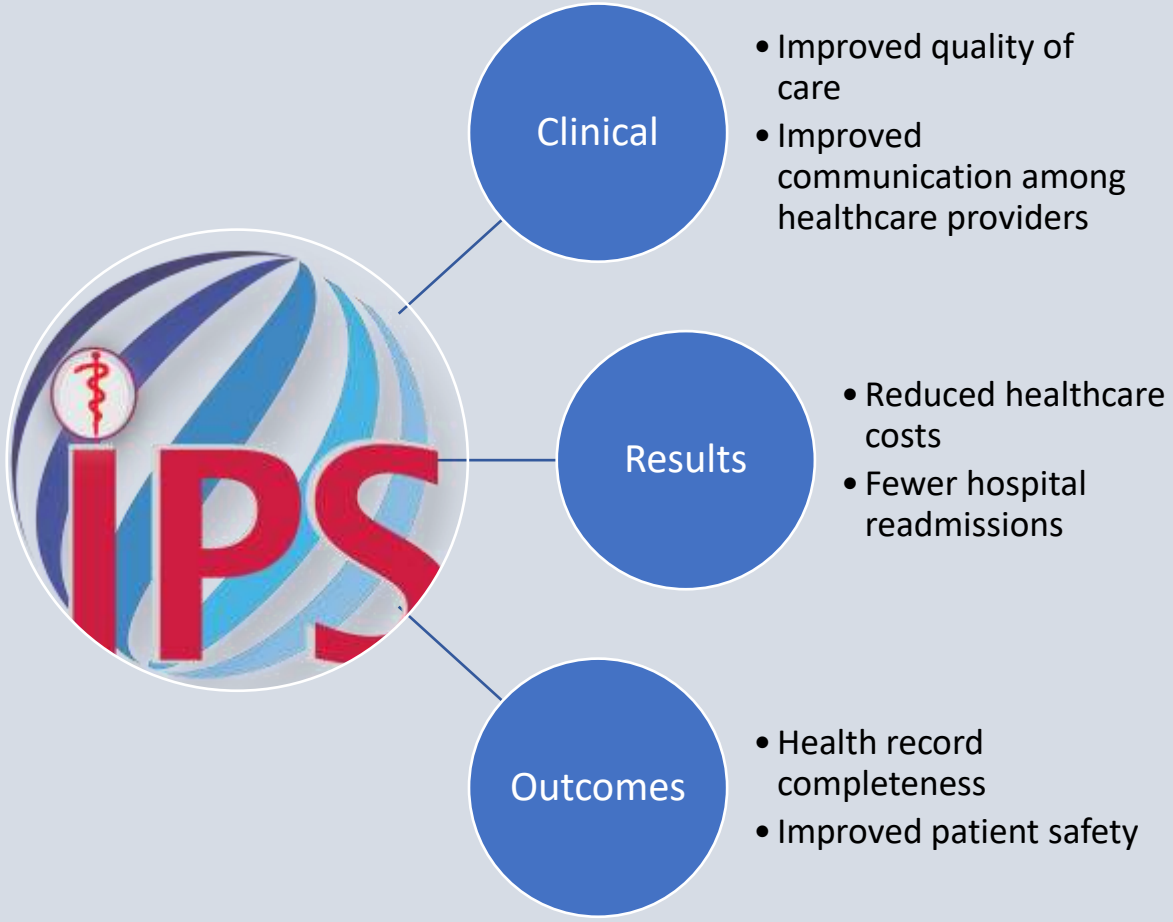
There is no “one-size-fits-all” for use

- Specific settings ask for specific designs, for example:
  - A GP out-of-hours office, where a patient calls in, might have a digital pre-triage, which can be accessed by the triage nurse
  - An Accidents and Emergency unit in a hospital, when a patient is brought in by an ambulance, might receive more detailed data directly from the ambulance (current vital signs, for instance)
  - A walk-in surgeon’s office for tourists, might have the ability to scan the mobile device of the patient and access the IPS directly

- Even though the setting is different the datablocks in the summary remain the same - using them will be different!

The Patient Summary – its clinical value

The clinical value of a summary



Systematic review of the literature

https://international-patient-summary.net/exploring-the-clinical-value-of-the-international-patient-summary-a-systematic-review/

Interviews to back up the findings

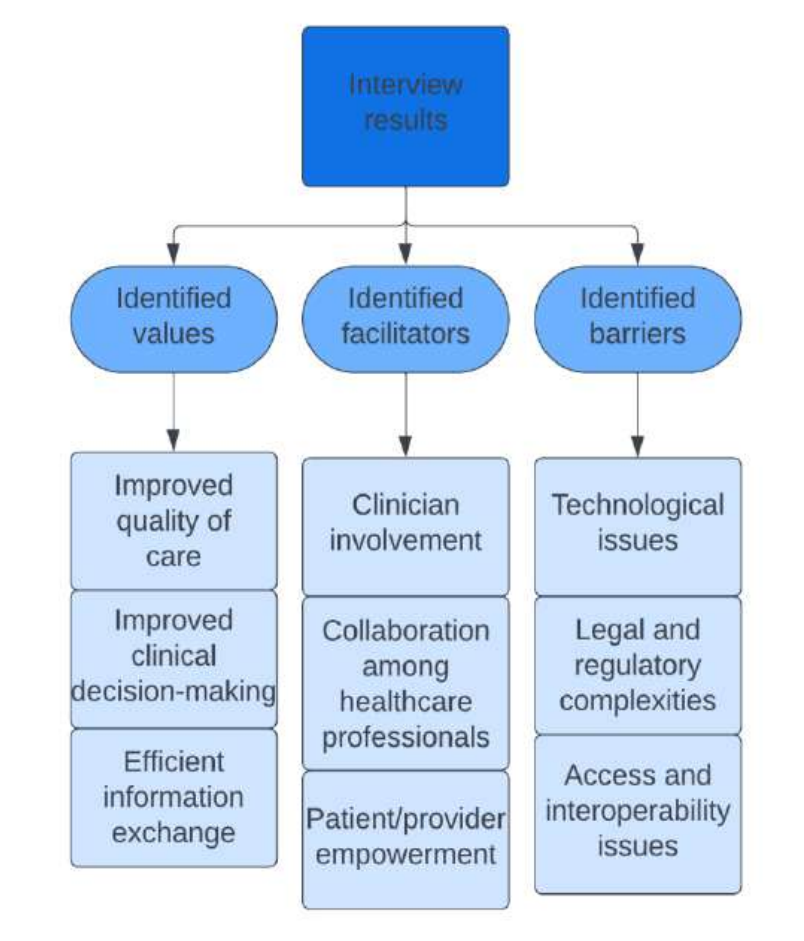
"I think it took 1600 keystrokes and 500 mouse movements to get through the patient file."

"I do not know anything about that person. The patient states that his own GP can share everything. That is a link to the local GP post, but I cannot see anything. I have absolutely nothing."

"Missing certain kinds of information is just not good. It really creates a risk for the patient. Having that information available is thus very useful."

"In any case, when developing such a system, I think it is important that clinicians remain involved at every step."

Recommendations

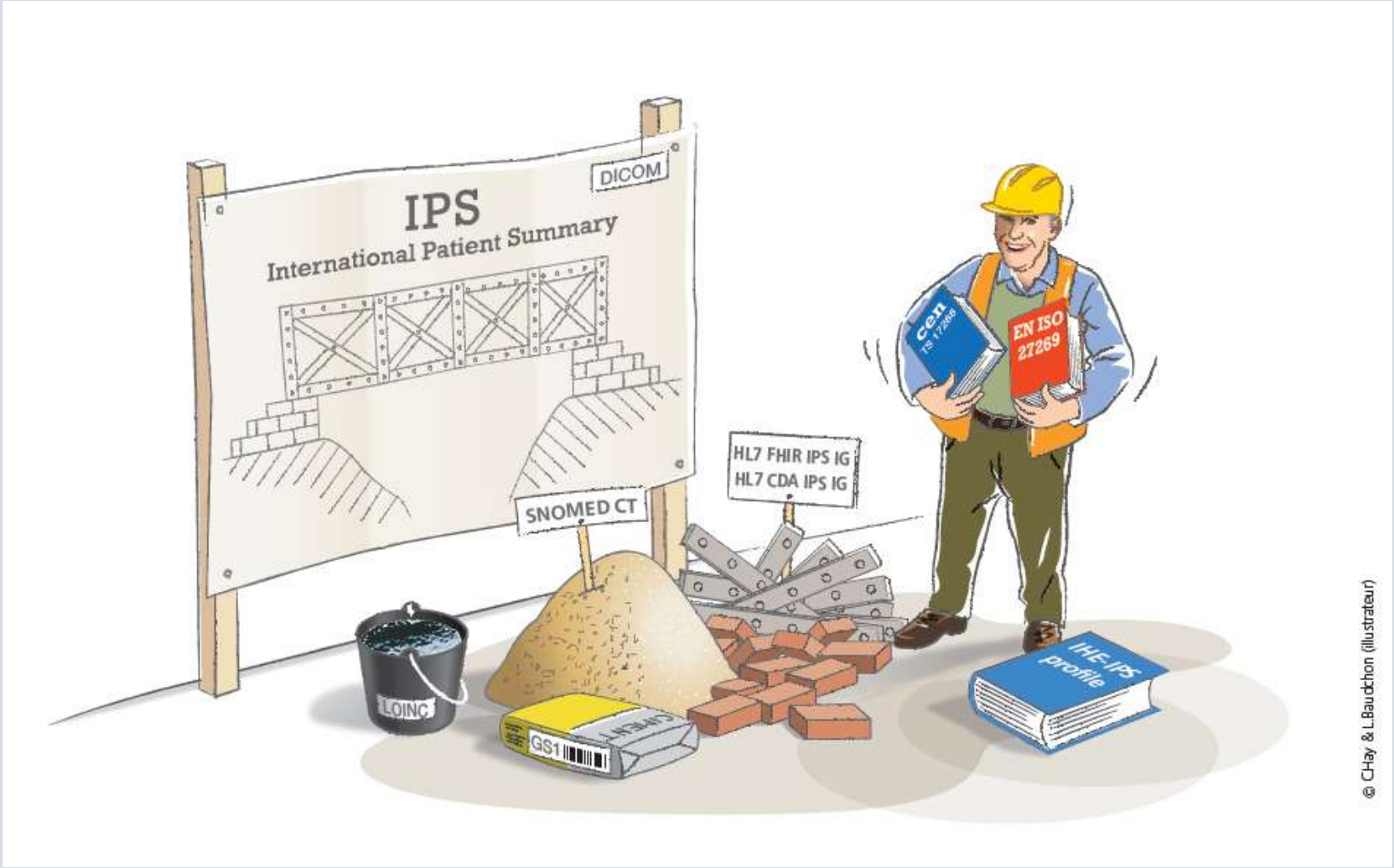


- The value comes from using the patient summary
- Awareness among professionals needs to be increased
- Experts need to shift their focus to adoption – the requirements and standards are sufficient for large scale implementation

Adoption interviews with clinicians
https://international-patient-summary.net/the-adoption-and-diffusion-of-the-international-patient-summary/

The Patient Summary – a set of standards

A resounding collaborative effort



EN ISO 27269 Health Informatics IPS

- Full title:
  - EN ISO 27269:2022 Health informatics — International patient summary (ISO 27269:2021)
  - ISO 27269:2021(en) Health informatics — International patient summary

- Defines the core data set for a patient summary document that supports continuity of care for a person and coordination of their healthcare.

HL7 FHIR Implementation Guide

- Full title:
  - HL7 FHIR International Patient Summary Implementation Guide
  - https://hl7.org/fhir/uv/ips/ - version 1.1.0

- Provides an implementation of the EN ISO datablocks with HL7 FHIR resources, including terminology bindings and other restrictions

- A FHIR Server can implement the $summary operation on the Patient resource to actually produce a FHIR IPS Document

IPS Clinical Terminology

- HL7 FHIR often references SNOMED Clinical Terms for terminology bindings
- SNOMED CT values are used in the EU Patient Summary pivot document to enable translation into all European languages
- SNOMED International agreed to provide these Patient Summary SNOMED terms for free – the IPS Free Set
- As of 2022, SNOMED also provides the IPS Terminology for free

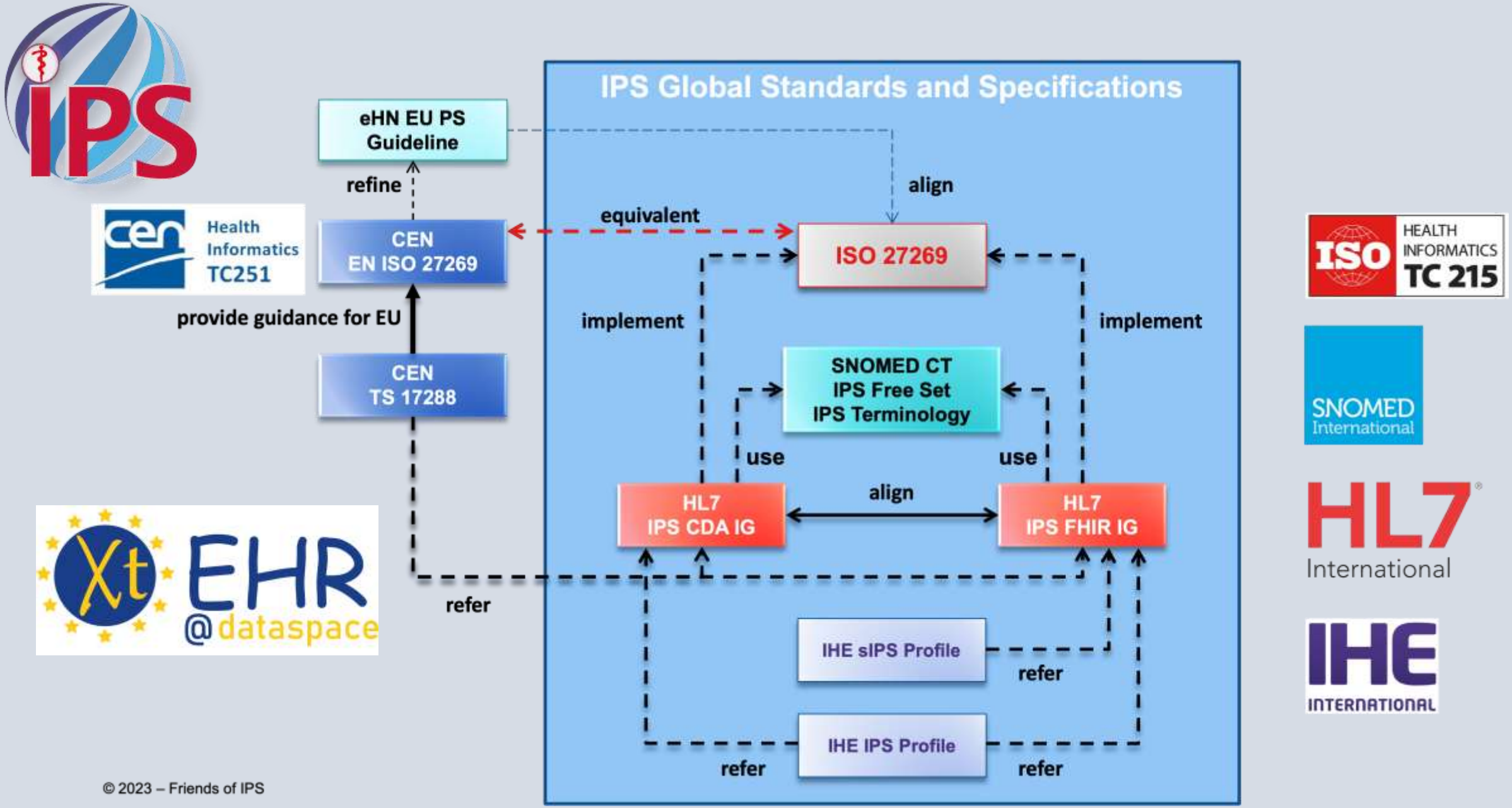
HL7 CDA Implementation Guide

- Full title:
  - HL7 CDA® R2 Implementation Guide International Patient Summary, Release 1
- Actually the first IPS standard to be published
  - The US Continuity of Care Document is CDA based
  - The European Cross-Border eHDSI pivot document is CDA based
  - The EU Trillium Bridge and the HL7 InterPAS projects both worked under the EU-US Transatlantic eHealth/Health IT Cooperation Roadmap to connect the EU and US patient summaries
  - The EU Standardisation Request for the Patient Summary was answered by CEN in close collaboration with HL7 and IHE, continuing the work of Trillium Bridge and InterPAS

IHE content and sharing profiles

- For purposes of conformance testing, IHE provides:
  - IPS profile – a content profile that provides testable conformance statements for an IPS document, both in HL7 CDA and in HL7 FHIR
  - sIPS profile – a sharing profile for HL7 FHIR IPS Documents, linking the IPS to the regular document sharing infrastructure that IHE describes

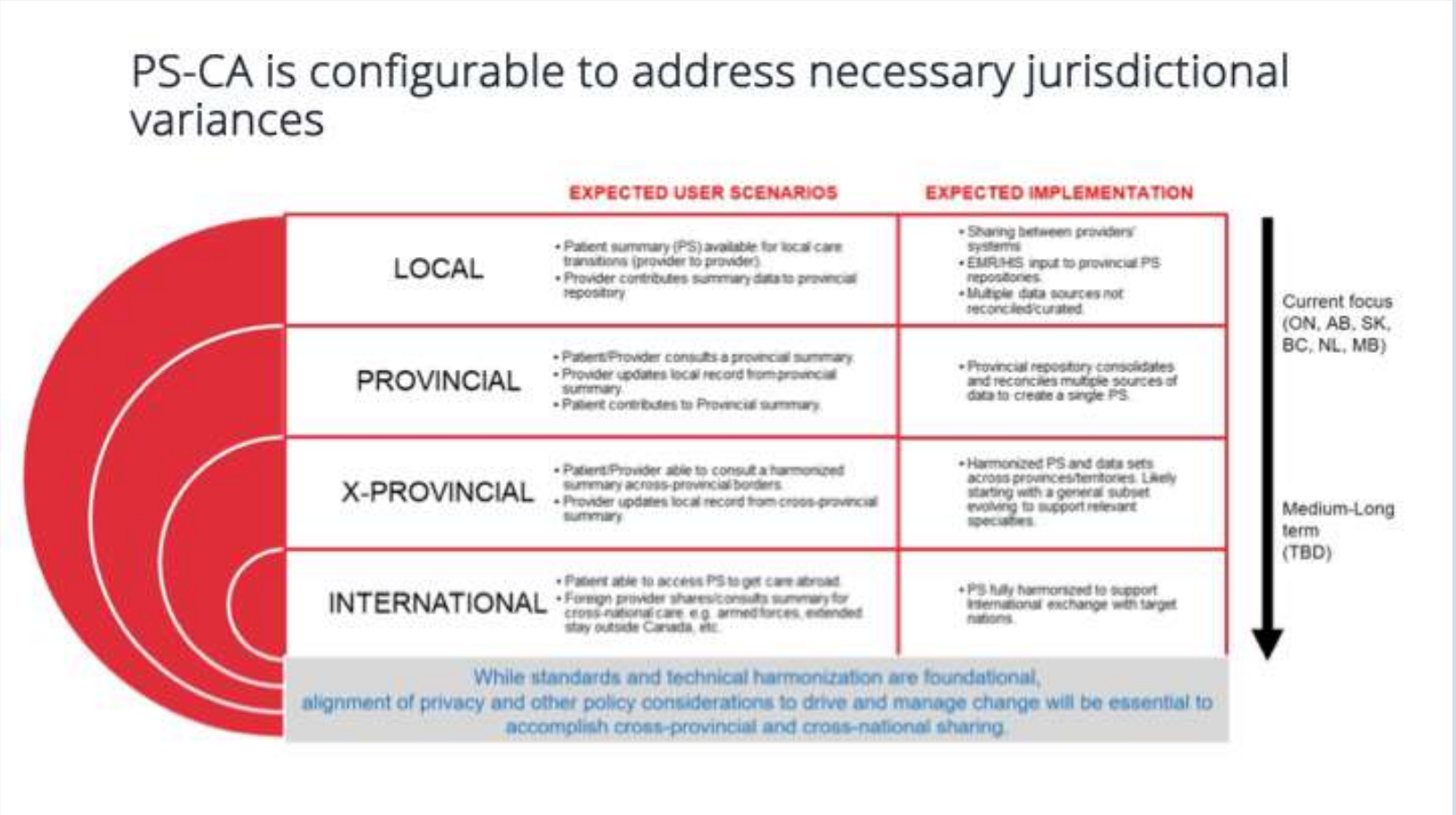
- IPS Theme during the IHE North America Connectathon 2025



The challenge of localisation

- G7 Countries have chosen to adopt the IPS
  - Canada is actively testing the PS-CA
- Europe still has its “own” EU specifications
  - HL7 Europe is developing a European Patient Summary specification
- G20 Countries have chosen to adopt the IPS
  - Australia is focusing on AU PS
  - Brazil is rolling out the IPS nationally
- GDHP has an active IPS project
  - New Zealand is rolling out the NZ PS for every kiwi
- WHO is piloting the IPS for the Hajj, using GDHCN
  - Saudi Arabia is receiving IPS from Malaysian and Indonesian pilgrims

Canada aims to cover variances



Non-breaking localisation

- Is a local version of the PS still compliant and usable as an IPS?
  - Should it be?
- Having different versions being maintained independently is a version management nightmare
- Having to support different versions as a global vendor is further complicating the already complicated multi-country software development life cycle

The Use of the Patient Summary

Different roads to using the IPS

- Maybe each jurisdiction needs to go through the IPS specifications and create its own implementation guides
- Maybe that’s what is needed to actually start using the Patient Summary
- But maybe, the “experts” advising the governments are so used to creating implementation guides, that they just don’t know any other way to start the implementation process
- Or the governments need to control the specifications that they want to reference in their legislation, mandating the use of the Patient Summary

How are YOU using the Patient Summary?

- Specifications
- Awareness
- Adoption
- Actual use

Thank You

robert@trace-health.nl

https://www.linkedin.com/company/international-patient-summary