The International Patient Summary Standards

Patient Summaries everywhere

Most healthcare providers already have their own version of a patient summary for use in their own organisations.   Many countries have national equivalents, albeit some more extensive and/or more mature than others.   So why bother to standardize?   And why now? And why the need for an international solution? And, assuming there are affirmative answers to be had to all of the above, how can it be delivered?

Patient summaries (PS) are concrete manifestations of a clinician's education and training.   The purpose of a PS is to provide a concise account of a patient's clinical history, either as an aide memoir for the author, to be used in a later consultation with their own patient, or to satisfy a request for information sharing, with subsequent review by another clinician who has to treat that same patient in a different context.

Either intention, makes the PS one of the earliest examples of data reuse; particularly if one considers the exchanged data to be an 'extract' or 'view', comprising **usable** and **useful** data from one or more pre-existing records.

Patient summaries are therefore ubiquitous. They are an important, integral, and even an inseparable part of the fabric of today's healthcare. Given the significance and intertwined nature of the PS, any attempt to impose an international standard is likely to be both contentious and disruptive! So…

Why bother to Standardize?

Patient summaries can be made more usable, more useful and effectively safer than they are now; a necessity given their increasing role in both the continuity and coordination of healthcare. Paradoxically, the success of the PS has led to a plethora of diverse implementations that make the necessary sharing of critical information at the point of care problematic for an attending physician, who cannot always rely upon the presence of core content unless (and not always) it is from their own system/organisation.

Standardization of the PS is not a big issue for those working entirely in a closed, uniform and single system, yet even these rarefied cases have to manage external in-coming and out-going communications with the wider ecosystem in which heterogeneous systems are the norm. But…

Why Standardize now?

Citizens (i.e. potential patients), patients, and clinicians, move around, perhaps much more than in the past. Certainly, patient expectations are higher, demanding the same standard of care when and wherever required. Healthcare providers and their responsibilities are subject to change, and this too requires data to be shared in a seamless way. Healthcare delivery is increasingly a team-support activity, often stretching across system boundaries, and the overwhelming complexity of the ecosystem cries out for simple solutions wherever possible.

Patient summaries are not rocket science. Yet in a time of Precision Medicine, wondrous imaging capabilities, magnificent advances in treatments and amazing analytics involving Big Data, not to mention all the PS systems already in existence, is it not ironic and, a little shameful, that we cannot yet transfer a relatively small, **agreed** dataset across system boundaries in a standardized way for the benefit of the patient and healthcare provider alike? Of course, it should be possible, but…

Why an International Patient Summary Standard?

The essence of the problem, and the solution, is not just technical; it is much more to do with 'agreements'. The myriad of existing systems, if not implying a reluctance to change, surely show that they have a way of doing things locally, in their own way. Certainly, it is understood that any international solution should readily support the local/national requirement, because that is where the bulk of the day to day information sharing occurs. Furthermore, local systems constitute significant investment in practice and often have buy-in from those in the healthcare professions who champion the specific content of a PS, rightfully requiring it to meet their specialist needs.

Europe has no mandate over its Member States (MS) with respect to the healthcare domain, but it encourages and facilitates mobility of its citizens across MS and therefore initiatives, such as an International Patient Summary (IPS) for cross border care, aligns well with key European policy. Furthermore EU-US agreements mean that such initiatives have more value and credibility if they are broadened to include partner nations engaging and participating in complementary projects such as Trillium Bridge (1 and 2).

How do we deliver an International Patient Summary?

Standardization is another form of agreement but deploys a formal consensus process.   It definitely takes much longer than putting together a set of preferences for 'my ideal PS', which exacerbates the confusion and hinders interoperability. Yet Another PS (YAPS?) is neither required nor helpful; it is just more noise.

The Standardization consensus process, however, does imply the existence of multiple, serious stakeholders. Not surprising, there are a number of concurrent activities pursing a similar goal in the PS space and some observers has likened the approach to establishing an IPS with the attempt to change a wheel on a moving vehicle!

Fortunately, whilst difficult, it is not as bad as all that. Through active, joint participation, three of the four major activities are under the leadership of the Standards Development Organisations (SDOs) and are mutually beneficial and compatible:

- The JIC Patient Summary Standards Set (PSSS) is not intended to be a standard in its own right; it is essentially an informative output that is intended to inform the stakeholders about existing or developing standards in the PS space. By contrast, HL7's IPS and CEN's IPS (the IPS Projects) are intended to be normative and relatively narrow in focus, taking on board relevant detail from the PSSS and contributing to the PSSS content as the IPS Projects develop the formal standards.   Furthermore, the IPS Projects are actively working together to produce a single compatible solution based on agreements made at the Oslo workshop organised by Trillium Bridge 1 back in 2016.
- The fourth project is the eHealth Digital Service Infrastructure (eHDSI) initiative for cross-border health data exchange, which builds directly on the outputs of the epSOS pilot with a view of providing implementations for European MS by 2019.

All four initiatives[1] rely heavily on the guidelines for a PS dataset, version 2 being published by the European eHealth Network (eHN) in November 2016. This useful guideline goes a long way to support the harmonization efforts of CEN/TC 251 and HL7.

---

[1] The JIC PSSS differs from the others in that it introduces extra items reflecting homecare requirements but those are outside of the IPS Projects' current scope.

The CEN IPS project will produce two standards; the first being a domain model for the IPS focussed on the use case of cross-border unscheduled care, and the second, a Technical Specification (TS), which will offer specific guidance for IPS implementation within the European context.

The first, prEN 17269, specifies "the core dataset for a patient summary document that supports continuity of care for a person and coordination of healthcare". It also contains the conformance rules that have to be applied to a derived model in order to comply with this standard. Joint participation has enabled a consistent approach with HL7 and eHDSI, and 17269 provides a means of deriving conformant implementations.

17269 does not overstate or undervalue its contribution, i.e., "due to its nature therefore, readers should be aware that the compliance with this standard doesn't imply automatic technical interoperability; this result, enabled by this standard, can be reached with the conformity to standards indicated in the associated technical specifications." An underlying standard (ISO 13940, Systems of Concepts for the Continuity of Care, 2016) underpins the given IPS scenario providing concepts and terms to support the goal of interoperability. The accompanying CEN TS 17288 will provide practical examples, showing how other standards (e.g., CDA, 13606 and FHIR representations) may use the prEN 17269 IPS to achieve technical and eventually semantic interoperability for the IPS.

The CEN IPS project team passed prEN 17269 to CEN Central Management in the beginning of February for translation and subsequent launch for ballot end of May. The CEN IPS Technical Specification 17288 is currently under development with the expectation that it will be completed by the end of this year.

The HL7 IPS project will deliver two implementation guides (IG) specifying how the IPS core dataset can be represented trough the HL7 CDA R2 and the HL7 FHIR standards.

The first guide (the IPS CDA IG) has been already successfully balloted and it is expected to be published as Standard for Trial Use (STU) shortly. This guide defines a set of CDA templates built on pre-existing CDA templates (HL7 C-CDA CCD (Continuity of Care Document); IHE PCC (Patient care Coordination); eHDSI, formerly known as epSOS) to be used for building an IPS document. These templates have been specified and published in ART DECOR® (https://art-decor.org/art-decor/decor-project--hl7ips-) to facilitate the templates' formalization and reuse.

The FHIR IPS implementation guide – based on FHIR R3 - has been recently released for the STU ballot (May 2018 HL7 ballot cycle) (http://hl7.org/fhir/uv/ips/history.html). The same conceptual content in both the CDA R2 and FHIR specifications, i.e. the IPS core dataset, has been used.

Both the guides share the same design principles in order to facilitate the alignment between CDA and FHIR implementations, without however attempting to provide or require capability for automatic transformation of instances from one standard to the other. Both guides provide support for multi-languages translations; give a strong attention to implementers; and specify the building blocks (CDA templates; FHIR profiles) used for creating an IPS document. Even if the intended use of these "building blocks" is the IPS document; there is a growing interest in looking at them as a library to be reused in other situations, as investigated for example by the European Trillium II project (https://trillium2.eu/).