

# Positioning the International Patient Summary (IPS)

The IPS Project has achieved far more than we had any right to expect! Consider the likelihood of two standards developing organisations (SDOs) working together on a topic as old as the hills, and just as common place, making considerable progress on a global stage, and creating four new, coherent and consistent standards within two years, with successful balloting and certain publication of all four within three years! Surprising but true.

The IPS Project was/is essentially a very successful partnership between CEN/TC251 and HL7; two SDOs that in the past have often disagreed or simply gone their own way; each with its own organisational culture that has resulted in different ballot cycles, different stakeholder engagement, and different policies. However, it is not the first time that collaboration has worked. In 2007, TC251 and HL7 (the third collaborative party being ISO/TC215) are credited with creating the Joint Initiative Council (JIC), which has also played a role in promoting the patient summary work.

The Council was charged with opening up dialogue between the SDOs and created a membership Charter to make a public statement of intent. In part, JIC was formed to answer the dissatisfaction from stakeholders at, what they saw as, duplication with the associated multiplying effect of having too many standards often covering the same areas and creating a mess of choice for the would-be commissioners and developers. At that time, interoperability solutions were not perceived as being served by the SDO activities, rather it seemed to many observers that they were making matters worse by overcomplicating an already complex field of endeavour with non-harmonized, inconsistent standards. JIC is not a formal standards developer in its own right but it has grown to encompass main-stream standards and profiling organisations in the Health Informatics domain, working in the background to restore credibility to the idea of 'joined-up' approaches.

Fast forward to 2015, JIC proposed the idea of creating informative guides as a public service and as away of attracting attention to its ongoing



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activities. JIC launched the San Francisco Declaration in April, "The JIC will contribute to better global patient health outcomes by providing strategic leadership in the specification of sets of implementable standards for health information sharing." [1]. The Patient Summary was chosen as the first topic, because it was clear that there was already considerable interest and consequently several initiatives underway across the world. This was particularly true in America and Europe where a Memorandum of Understanding was established for EU-US cooperation. Some of these activities already involved both CEN/TC251 and HL7, who were acting separately in projects on Patient Summary Standards.

CEN IPS was a TC251 proposal made to the European Commission in 2015; the actual work started in September 2016. It had two principal strands; the first was to enable a team of five, comprising an administrator and four technical experts, to participate in International activities on Patient Summary standardization and the second was to formalise the existing guidelines from Europe, turning them into an international standard. This second part may seem to have been a tall order, but a critical success factor was that the European guideline was already a basis for substantive work in Europe, as well as in the HL7 INTERPAS project, and was referenced too by the JIC guidance document.

The European project Trillium II [2] facilitated a meeting between the two SDOs in Oslo in April 2017, where we established a common vision, mission and scope for the International Patient



Figure 1: <http://bit.ly/IPS-Discover>

Summary with CEN IPS and HL7 IPS cementing their effective and successful collaboration [3]. The rest, as they say, is history. It is, nevertheless, worth noting that:

- The International Patient Summary is not only for cross-border care, but can equally support the exchange at local, national and regional levels.
- The International Patient Summary Project's thinking has evolved. The IPS is now also perceived as a catalyst and model for a toolkit to be used in a variety of different circumstances, selecting and extending the IPS data blocks for each individual use case.

The four IPS Specifications have been created, balloted, all ahead of schedule, and all this was done by each SDO playing to its strengths rather than competing. What is more, with the new deal between HL7 International and SNOMED CT, and the intention of CEN to move the IPS Dataset into ISO, the IPS collaboration can be seen as the practical embodiment and value of the joined-up philosophy of JIC. CEN IPS had its final funded stakeholder meeting in Brussels on March 19th, 2019.

All that having been said, we are now at the beginning of joint IPS development rather than at its ending. The dataset specification will be refined and it will mature in an incremental, planned way to give confidence of stability to the vendor and maintain relevance for the healthcare communities.

The creation of beautiful, consistent specifications is one thing. SDOs now need to position the IPS for acceptance, for adoption and for real use, and so must find effective and efficient forms of dissemination, of sustainable development and, last but not least, of productive governance:

- Dissemination has been an on-going part of the IPS Project from its inception, where the CEN and HL7 teams have presented, written and explained what the IPS is, what it can do, and

why it is so important. One attempt to capture this story, and to ensure the compelling arguments and rationale are not lost, is the CEN IPS Prezi (see Figure 1 and URL), which is intended to complement and showcase the normative standards; for IPS to have the intended impact, the story and standards must address multiple audiences, as only a relatively few will avidly read the specifications!

- The UN [4] defines 'Sustainable Development' as development that "meets the needs of the present without compromising the ability of future generations to meet their needs". We believe that the IPS approach offers that opportunity; we should not squander it if we wish IPS, and initiatives modelled on it, to have a future; one that will benefit us, both as individuals, i.e., potential subjects of care needing a good quality summary and, more generally, as joint beneficiaries from establishing better continuity and coordination of healthcare.
- The IPS Project began work as a collaborative of two SDOs, but has since attracted others, who see value in the collaboration and outcome, and each with a specific role to play going forward. The Trillium II deliverable [5] on the IPS governance suggests a future, potential role for JIC; it is our mission then - should we choose to accept it.

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## References

- [1] JIC, <http://www.jointinitiativecouncil.org/>
- [2] <http://www.estandards-project.eu>
- [3] CEN/TC 251 & HL7 Agreement to IPS collaboration, 2017, <http://bit.ly/IPS-Oslo-agreement>
- [4] United Nations. 1987. "Report of the World Commission on Environment and Development." General Assembly Resolution 42/187
- [5] Stegwee R, Trillium II Deliverable. 2019, WP5, D5.2 Towards an international patient summary standards Governance Framework: managing requirements, intelligence gathering, and updates (an abstract appears in this newsletter).