

Report 31<sup>st</sup> May 2019

# The Report from the International Patient Summary (IPS) Stakeholder Workshop

CEN Offices, Rue de la Science 23, Brussels, 19<sup>th</sup> March 2019

Stephen Kay, PhD, MSc, FACMI, FBCS  
CEN IPS Project Lead

## Executive Summary

This report is of an open meeting, that was the second stakeholder event that CEN had promised to deliver within the EC contract SA/CEN/GROW/EFTA/000/2015-16.

That contract was the outcome of a successful proposal by CEN/TC251; it had two interdependent objectives:

1. To facilitate participation in regional and international work on the patient summary, and
2. To formalise the eHealth Network's (eHN) Guideline on the patient summary dataset, transforming it into an international standard, with associated guidance as to how that standard should be implemented within Europe.

The first objective enriched the *CEN IPS* project, keeping it faithful to the European needs and to our shared context going forward. This workshop was an important part of this. The first objective also enabled the CEN team to actively participate in concurrent international activities and regional initiatives such as the eHAction Roadmap.

The second objective was rather daunting. It was achievable only because the eHN guideline was already considered to be an important part of existing regional and international projects. However, as with the history of the ubiquitous patient summary, these activities were not wholly consistent with each other, their differences posing potential problems for safe exchange of personal healthcare data.

*CEN IPS* delivered two consensus Standards for the IPS ready for ballot; one concerned with an implementation independent standard of the IPS Dataset and one concerned with guidance material regarding how the international standard should be implemented in Europe.

The workshop reported on the success of the IPS Project. The report from the workshop follows the original agenda and is structured into five sets of contributions, all with the theme of 'beneficial, collaborative working':

- Beginning Collaborations
- Regarding Past and On-going Collaborations
- Regarding New and Potential Collaborations
- Helping Collaborations Work
- Progressing Future Collaborations

Further work remains with building trust regarding implementation and adoption. In particular it was noted that more work is necessary with respect to IPS governance, and with meeting the global aspirations of the IPS; with regard to the latter, it was noted that the *CEN IPS* Dataset is to be fast-

Report 31<sup>st</sup> May 2019

tracked as an ISO Standard once the European one has passed ballot. A different dissemination approach, intended to be more accessible and inclusive to stakeholders, is also introduced.

## Introduction

This workshop was the second event of its kind and an integral part of the stakeholder engagement, requested by the CEN/TC 251 proposal for the IPS work. The workshop agenda was structured into five sets of contributions, involving different aspects of collaboration with *CEN IPS*. These are reported here as:

- Contribution 1 introduces the context, the different stakeholders, the awarded contract, and reports on the nature of the deliverables and their status. It stresses the important role played by eHN and their input of the patient summary dataset is discussed in this introduction.
- Contribution 2 introduces our long-standing participation in European projects, particularly focusing upon the on-going HL7 collaboration in Europe and in the States. IPS as an open Collaboration framework is introduced.
- Contribution 3 introduces new and potential collaborations, involving the eHAction Roadmap that has already included consideration of the IPS, the IHE testing frameworks, and the proposed European EHR exchange format.
- Contribution 4 looks at the challenging issues going forward. This was a facilitated open discussion at the meeting that considered acceptance and adoption of the IPS, governance and sustainability, and how to further the relationship within the eHAction Roadmap activity.
- Contribution 5 considers Next Steps and suggests paths for future collaboration. Building on outputs from Contribution 4 in particular, value propositions are considered for IPS, ways of managing on-going change are discussed and consideration is given to how information about the IPS can be disseminated in an economical way, and one intended to be more easily accessible by multiple stakeholders with different needs.

## Contribution 1 (Beginning Collaborations)

CEN/TC251 presented a proposal to the eHealth Network (eHN) in November 2014. The substance of the presentation was twofold: to encourage further SDO collaboration within Europe by establishing a European eHealth standardization platform, similar to the Joint Initiative Council (JIC), and secondly to focus that activity by working together on the Patient Summary Guideline, first produced by eHN in 2013.

The SDO collaboration platform did not materialise, but the EC looked favourably on a CEN proposal to formalise the eHN guideline and awarded the present contract in December 2015. The proposal had two main objectives, the first was to do with collaboration and participation in regional and international patient summary activities, and the second was to produce European and International

Report 31<sup>st</sup> May 2019

consensus standards based on the eHN work. The first objective, relating to collaboration and participation, permeates the proceedings of this whole workshop and is discussed in more detail throughout.

### The eHealth Network and the beginning of the IPS

In this first Contribution, the focus is upon the eHN, their patient summary guideline, and the two deliverables from CEN/TC251 based on that guideline. The present status of the two International and European standards are also given here.

The first eHN Guideline related to Patient Summaries was approved in 2013. In November 2016, a new version of the Guideline was adopted. The first *CEN IPS* project team meeting was in September 2016; a brief delay was inevitable as *CEN IPS* was committed to understanding the new version and using that as the basis for the IPS Dataset. In essence there was little change to the actual dataset between the two versions, but that fact was welcomed, suggesting that the second version was more mature and therefore a better candidate for standardization. However, version 2 gave more freedom, and the three-layer hierarchy was retained. *“Everything is vague to a degree you do not realise till you have tried to make it precise.”*<sup>1</sup> The CEN project team became quickly aware of this truth, discovering that the degree of detail required for a standard, and for any implementation that would use such a specification, far exceeded the original guideline.

### The adoption of the eHN Guideline for the IPS

*CEN IPS* based its data model on the eHN Guideline, as specified by the contract, but it extended the depth of the hierarchy to eight layers whilst ensuring that it fully covered the breadth of the expressed content. The original concern for the eHN was to do with cross-border exchange of health data, following the epSOS pilot project, and in line with the EC policy and Directives. Further refinement of this cross-border scenario was made to consider the patient summary being primarily for ‘unscheduled care’, and the eHN guideline suggested this might be where the greatest stakeholder value might lie for a Patient Summary.

However, the fact that the first objective permitted international participation and collaboration enabled *CEN IPS* to also look at deployment projects in Europe and in the States that had already attempted to interpret the guideline for their own implementations. This knowledge helped us formalise the original guideline in a way that would enable important existing implementations to later conform and to provide a point of harmonization that others could aim for.

Furthermore, reverting back to the base, more general, use case of ‘providing a patient summary at the point of care’ enabled *CEN IPS* to keep its contracted scope whilst satisfying the four scenarios of ‘unscheduled/scheduled care’ (i.e., all care) and ‘cross border/within borders care’ (i.e., anywhere, e.g. local as well as international usage). Refining our focus and concentrating upon all four scenarios did not dilute the IPS work. On the contrary, by considering all four scenarios, *CEN IPS* has delivered standards with even greater value for more stakeholders. The new focus permits a consistent approach, enabling Member States to use the same means for local use, wherein the majority of their healthcare transactions occur, as well as for cross-border purposes if and when required. More recently, others have suggested that the IPS will also be as important for scheduled care as it was supposed to be for unscheduled care. These actions effectively mean that local and international

---

<sup>1</sup> Credited to Bertrand Russell, a mathematician and philosopher.

Report 31<sup>st</sup> May 2019

activities can be in sync in terms of the IPS Dataset, permitting alignment and broad stakeholder engagement in governance going forward.

*CEN IPS* managed to distil the essence of the International Patient Summary (IPS) to a description of its unique purpose plus a standardised set of ‘core IPS Data Blocks’ that could be used in most, if not all, care contexts (i.e., what the CEN standard calls ‘condition-independent and specialty-agnostic’ requirements). The IPS Dataset has **required**, **recommended** and **optional** data blocks but is extensible if conditions and specialties require. This arrangement satisfies the eHN guideline for ‘a minimal but non-exhaustive dataset’. It also enables the standard to designate the ‘cross border’ data block as being optional for local purposes (removing burden and overheads for the majority of uses) but making sure it is ‘required’ for any ‘cross border’ application.

### IPS separation of Data from Implementation, and Balloting

Another key decision made by *CEN IPS* was to make the data model entirely implementation independent and this includes any binding to any specific terminologies. The IPS Dataset did not use UML notation, making the content easier to read and, hopefully, to understand. These steps permit the IPS Dataset to be used by all and thereby permits it to become a global standard without such constraints of particular exchange formats or licensing and/or availability of specific terminologies within a country.

The two CEN standardization deliverables (prEN 17269 ‘The International Patient Summary’ and DTS 17288 ‘The European Guideline for Implementing the IPS’) were balloted in the Spring and Summer respectively of 2018, and both received 100% approval by the voting Member States in CEN. However, along with their approval, also came suggestions for improvement, which we tried to accommodate for this iteration of the standards. These requests, however, involved some technical changes and so to remain completely transparent, it was decided that the improved versions should be submitted for a second ballot in Spring 2019, and the expectation is that they will pass and proceed to publication by the end of the year.

### Contribution 2 (Regarding Past and On-going Collaborations)

CEN/TC251 entitled its standard work as the International Patient Summary (IPS) recognising that its success depended on reaching out to other international activities and that the resulting application had to be global to be truly effective. *CEN IPS* became the project’s name for all the activities to be carried out under the EC contract. Participation in patient summary activities in Europe and further afield, were not only required by the contract, but were also very necessary to ensure that the work to be undertaken remained relevant to European Stakeholders and that the dataset work in the eHN Guideline was faithfully represented in any international development.

*CEN IPS* was involved with a number of H2020 European projects that were either concentrated on standardisation or which had some relevance to the IPS. The engagement in these European projects had the dual purpose of the team learning from, and the team informing different regional stakeholders as the *CEN IPS* work progressed.

One particularly fruitful outcome of the funded participation was to look further afield, particularly with the focus upon the EU-US MOU. This activity led indirectly to exploring the past and current work of HL7, and this directly resulted in the creation of the IPS Project, which comprises both *CEN IPS* and HL7 IPS. This is now an on-going, successful collaboration between the two Standards Development Organisations (SDO). The collaboration officially started in April 2017, brokered by the Trillium II EU

Report 31<sup>st</sup> May 2019

Project, when the two SDOs agreed a combined mission and further agreed a set of qualities and principles for the IPS work and these statements have served us well in the design and the implementation of the IPS exchanges. The agreed principles established for the IPS standards are:

- Be Implementable
- Be globally applicable
- Be extensible and open
- Be sustainable

It may have been possible for non-HL7 members to do CDA and FHIR implementation guides of IPS. However, this would be very sub-optimal as the HL7 expertise, experience and their tooling already exist, and they were already engaged in Patient Summary work. It would also have made for a poor collaboration; it was decided at the outset that each SDO should play to its strengths, and this has worked exceptionally well with four standards (two from CEN, two from HL7) having been produced in 2 years and which are all scheduled for publishing in 3 years. The HL7 Implementation Guide for IPS (HL7 CDA IPS IG (STU)) has been published and the FHIR Implementation Guide has passed ballot and is expected to be published by the end of this year.

The IPS is not a product of a restricted team but part of an open, extensive collaboration. IPS is serving as a collaboration framework for different SDOs, with IPS taken as a reference use case.

HL7 has worked with SNOMED International to obtain an IPS Free Set of clinical terms, which have been available in drafting stage (since February) and will be publicly available from SNOMED in June 2019 to the IPS Projects and to eHDSI.

## Contribution 3 (Regarding New and Potential Collaborations)

### eHAction Roadmap

Part of the Joint Action to Support the eHealth Network, an initiative was launched to provide a roadmap on future use cases for eHDSI. The *CEN IPS* team was invited to participate in the first Roadmap workshop in Berlin in 28<sup>th</sup> November 2018. The IPS work was seen as a step along the way, and in part the aim was to position the IPS activity within a much larger context that considered the whole raft of work concerning Digital Health in Europe. In part, that first meeting was also an opportunity to reach out to both the eHDSI and CEN communities to exchange information and for them to become reacquainted with each other's work programmes. The following day was a *CEN IPS* open meeting, to which the EHAction participants were invited, and the focus was on how the IPS Project could support the Roadmap and the eHDSI going forward. The meetings were presented as a single event to reflect the mutual benefit that could be gained from closer collaboration.

The Roadmap was updated to version (0.5) after a two-day, joint meeting with *CEN IPS* on the 18<sup>th</sup> and 19<sup>th</sup> March 2019 in Brussels. This version of the Roadmap is comprehensive, covering 'Policy and Strategy Definition', 'Value Chains and Business Models', 'Communication and Engagement' and 'Products and Operations' and considering the opportunities, and challenges of each before making recommendations. Factoring in pragmatics, "the envisaged Roadmap for eHDSI would apply earliest from the beginning of 2020, which corresponds to the current planning of Wave 4 of CEF eHealth."

The Roadmap recognises the importance of standardization and of the SDOs, but recognises too that they are part of a much wider process. SDOs should not operate in splendid isolation, indeed they cannot survive in such a rarefied state. Good 'Connections' and 'Communications' are not just topics for specifications to achieve interoperability but are

Report 31<sup>st</sup> May 2019

essential if they are to be used effectively by engaging stakeholders, such as governments and end-user communities... “There is a need to improve dissemination, education, training around standards and the decision-making processes in standardization.... Provide knowledge on used and recommended standards and tools for development, improvement and adoption for ... solutions” pages 13/14 D6.1 version 0.5.

One set of specific recommendations from the Roadmap’s take on ‘Interoperability Assets’ is to use the *CEN IPS* Data Blocks as the beginnings of repository of ‘consented building blocks’ of clinical information. More generally, throughout the Roadmap document, there are many references that resonate with the IPS qualities related to the data and tooling (e.g. p9), its principles related to bridging policy and implementation and removing misunderstanding of SDO collaboration/position vis a vis the rest of the community (e.g. p10, p18), and its incremental, progressive approach with consensus-building (e.g. p20, p22), used to maximise clinical relevance and to enable common understanding across a wide spectrum of stakeholders (e.g. p15) (revision 0.9).

### Conformity Assessment of IPS Implementation

Going forward, how do we assess the conformity of the IPS implementation? The IPS Dataset provide an abstract definition of a Patient Summary from which derived models are implementable. A Patient Summary Implementation shall be an IPS Document<sup>2</sup>, comprising six required IPS Data Blocks, i.e., Patient Attributes, Allergies and Intolerances, Medication Summary, Problems, Provenance and Cross Border (conditional). There are various terminologies that can be used, and a set of scenarios with the use case. These may be extended. There are specific details in the cross-border data block that will be country specific, and two standard implementations at this point, i.e., CDA and FHIR.

IHE leads the Euro-CAS project which is developing a conformity assessment scheme for Europe. Its objective is to promote the adoption and take up of interoperability testing of eHealth solutions. It may be appropriate for IPS, given that it already uses some of its tooling for eHDSI.

### European Electronic Health Record Exchange Format (EHRxF)

In February 2019 there was a Commission Recommendation (6.2.2019) for EHRxF. The objective is to produce a Framework for cross-border exchange of EHRs in order to achieve secure, interoperable cross-border access and exchange of the same. The Framework will include a set of principles to govern access and exchange, provide a baseline for an exchange format and to define an iterative process to elaborate the exchange format.

The principles include Data protection considerations related to legal and policy concerns, but also security, audit and continuity of services. The *CEN IPS* did consider GDPR (see <http://bit.ly/IPS-GDPR>) but these other important principles were outside of the project’s given scope. The exchange format (EHRxF) should consider these elements and in doing so, will provide much needed support for successfully sharing clinical data safely.

*CEN IPS*, or at least the patient summary, is part of the baseline. In the public consultation on EHRxF, CEN/TC251 strongly recommended that this initiative should build upon the IPS work to avoid

---

<sup>2</sup> ‘Document’ is a common, well understood concept in this domain. The IPS Document is not a particular implementation pattern of communication; it applies to the structure and organisation of the IPS Data Blocks.

Report 31<sup>st</sup> May 2019

reinvention. This includes the *CEN IPS* Technical Specification that provides the European Guideline for IPS implementation using the ReEIF to structure its guidance.

## Contribution 4 (Helping Collaborations Work)

The facilitated discussion focused on the conditions for acceptance of the IPS across Europe, the rationale for adoption, some key questions to be answered and the next steps to take.

### Conditions for acceptance

For Member States to accept the IPS as a common standard, it needs to be clear which standard we are talking about: just the CEN logical standard (i.e., the IPS Dataset with structure and business rules), or also the CEN Implementation Guideline for Europe and the HL7 CDA and HL7 FHIR implementation guides? The process by which the standard was developed and the stakeholders involved, especially from a patient and health care professional background, needs to be clarified. Only then can a process be started to try and reach consensus among the Member States. Awareness of the standards and the process by which they were developed is key in moving forward together.

This could be the starting point of a huge transition, in which common structures for personal health and care data are implemented across Europe. It means that national specifications for patient summaries and/or electronic health record data need to be based on the IPS standards. This is already being targeted, because the national specifications need to be compliant with eHDSI in order to fully support cross-border exchange of patient summaries. However, national specifications may be considerably broader than the eHDSI. The IPS standards could guide and inspire this wider scope. The business case for such a huge transition needs to be worked on from a number of perspectives.

### Rationale for adoption

From a local operational perspective, there is a need to connect unplanned (eHDSI) care with planned care (IPS). Also, linking cross-border with local/national specifications will increase the volume of patients for which a standardized patient summary will be relevant and useful. It may even be a first step towards full exchange of electronic health record data, as envisioned by the EHRxF initiative (in which the IPS is positioned to be a key component). In that sense the discussion on adoption of the IPS is quite timely.

For eHDSI to adopt the IPS, the business case for the transition to IPS needs to be developed from the perspective of the participating Member States, as their needs drive the further development of the eHDSI. The standards should strengthen the eHDSI.

In general, a number of Member States have already recognized that going global is good. A common policy is in place to move toward international standards for several reasons: 1) the country gets better access to innovations from other markets; 2) the market for local players is extended to an international scale; 3) healthcare problems (e.g. disease) do not recognize a country's borders.

### Some key questions

During the discussion a number of questions were raised that need further clarification:

- Is the IPS truly global, or is it limited to the policy level in the EU-US collaboration on eHealth?
- Are we actually all moving toward the IPS standards, or is it still in the decision phase?
- Can we establish "joint" ownership of the standards between standards developing organizations (SDOs) and the users of the standards? What does it mean that an SDO (such as CEN, HL7 or SNOMED International) owns a standard?

Report 31<sup>st</sup> May 2019

- How can SDO's and competence centres work together on governance and maintenance of the standards to clarify definitions and semantics in a controlled way that does not overburden member states?

### Next steps

As a first step, an IPS presentation needs to be held at one or more of the eHDSI member state expert group meetings. This is already in discussion so an invitation might be forthcoming.

The next step would be a detailed comparison between the current eHDSI PS specifications and the IPS standards (including the HL7 CDA Implementation Guide). This would clarify the "distance" between the current and the standard specification.

A joint workshop in which Member States share their current experience in the implementation of the eHDSI PS will inform the added value and the requisite timing of moving forward to an IPS implementation, in which local and cross-border specifications come closer together.

### Contribution 5 (Progressing Future Collaborations)

This last *CEN IPS* workshop should not be regarded as the 'beginning of the end'. Rather, it is the 'end of the beginning' in that whilst the current funding of the *CEN IPS* project is nearing its close, there still remains much to do, both by CEN/TC251 and the many important stakeholders of the IPS.

### SDO Challenges

From an SDO perspective, standardization needs to be more visible, relevant and proactive in the socialisation of the standards it develops. SDOs are a significant part of the coordination efforts within Digital Health, but only a part; the implication is that there is a wide spectrum of activists that contribute to the whole endeavour and need to communicate better if any coordination is to be effective. The eHAction Roadmap activity has recently highlighted the problems of communication that exists in some Member States between standardization committees in those countries and those who participate in the eHN and within deployments like eHDSI. The problem of miscommunication is deeper, impacting the whole process from understanding requirements, acting together to produce relevant standards, through to the tasks of evaluating outcomes and the consequences for sustainable adoption and use. The SDOs need to be more agile and out-reaching in their consensus processes. Too often, SDOs have used an outdated academic standard of quality, seeing publication as the end goal, rather than considering impact factors as the academics now attempt to do.

*CEN IPS* has successfully met the contracted requirements and done so within the time line set<sup>3</sup>. However, we see the published deliverables as being outputs and stepping stones, rather than outcome and a certain destination. The IPS Project would argue that is only when the IPS standards are used in practice will we be in a position to consider outcomes and benefits of the IPS to citizens and to healthcare providers. And then, only if we remain open and transparent, and consider the richness and difficulty of the ecosystem. These are the principles that *CEN IPS* and HL7 IPS signed up to with its common mission statement in 2017 and that has not changed.

---

<sup>3</sup> The contract did not require us to have actually published the standards, only to have them ready for publication. However, as a direct result of the second ballot requirement for transparency we asked for an extension without additional funding. That has been accepted by the EC and we now formally close in October 2019.

Report 31<sup>st</sup> May 2019

## Change and Governance

The fact, however, that there are many different capacities, capabilities and expectations around the IPS, means that the IPS specifications will need to evolve. The process of change with change requests will have to be governed. The fact that SNOMED has now granted a free flat set of terms for IPS implementations, mean that there are now three SDOs working together<sup>4</sup>. There are also clear indications, arisen in the wake of this workshop, that the Joint Initiative Council will promote IPS and that ISO and IHE will also formally participate in the next stages of the IPS Project.

Managing changes is a known challenge to all human endeavour. We can presume that a single IPS Dataset to which all implementations conform will simplify the process, improve the quality of the data, reduce burden on healthcare providers, but we are not there yet. Even when we reach that prized objective, we will still need to address the issue of governance and change management. For example, *CEN IPS* has decided to do a second ballot to ensure transparency, even though the changes were from Member States that fully endorsed the IPS Dataset. This process has improved the document but has also impacted the publishing date of this first iteration.

The fact that the IPS Dataset is extensible and permits progressive and incremental changes as part of its design, helps to ameliorate the pain but does not completely avoid the need for efficient processes that are sympathetic to the consensus issues of capacity and implementation. The flexibility of the IPS incremental approach also carries a potential threat, with advocates labelling everything a 'patient summary'. This threat has to be countered as the IPS has a particular purpose that should be immutable; the IPS Data Blocks can indeed be used and reused for other applications, and the condition-independent and specialty-agnostic qualities of the IPS are to facilitate and maximise usage in very different circumstances. However, use of the IPS Data Blocks does not mean that the artefact is an IPS; for example, a discharge document is not an IPS despite having some elements in common. This separation of specific purpose (i.e. use case') from use-case-independent data blocks encourages the establishment of a shared library or repository to prevent endless reinvention.

From the IPS perspective, a minimal set of Data Blocks is in keeping with the eHN guideline, with the concept of a summary for an attending clinician, and also provides an opportunity to focus on that set to improve the quality through shared governance of the data. Conversely, there is also an opportunity to slim down the current 'minimal' set in later iterations, by removing data blocks concerned with, for example, a person's identity, with the document's provenance, and even with the 'cross border' data block; whilst these are extremely important data, they are not specific to the definition of a 'patient summary' and there is a strong case to be made that these general, use case independent datums should be given priority to ensure consistent usage across the spectrum of Digital Health applications. The IPS will use them and be the better for it.

## The Value of the IPS

Value and value propositions are difficult to quantify in Digital Health. The European H2020 project VALUEHEALTH (Grant Agreement number: 643847) was concerned with, "Establishing the value and business model for sustainable eHealth services in Europe". Using the value-chain approach, it derived the following two 'values' for the exchange of ePrescriptions and patient summaries:

1. "Better informed and safe care, and continuity of care, when patients seek care abroad.

---

<sup>4</sup> The fact that SNOMED is being used by the HL7 implementation guides does not restrict the IPS being used by others with no licence or desire to use SNOMED.

Report 31<sup>st</sup> May 2019

2. A borderless market for national health and social care innovation and the ICT industry."

We would echo these 'values' but make them more specific, and locally applicable, to the IPS Project:

"IPS: A means to unlock health data exchange, in a step wise fashion for:  
Continuity of care, and Coordination of care"

### New Developments for IPS

As well as the separate but closely related SDO products from CEN and HL7 there is also a joint product going forward understanding how a computable model of the *CEN IPS* Dataset Standard is of value. This development (i.e. the text becomes a program), if it succeeds, will ensure that misinterpretation of the standard (and others that may follow) will be greatly reduced, as well as ensuring much better testing in the future. Animating specifications has long been a goal in Computer Science, the IPS activity may realise this goal in the not too distant future. However, there are still issues relating to business concerns of copyright and charging.

Since this workshop, ISO TC215 Health Informatics has shown a great interest in taking the *CEN IPS* Dataset standard forward as a fast track standard. Indeed, a resolution at its plenary meeting in Sweden, 17<sup>th</sup> April, was passed unanimously (20 out of 22 countries (including India and China), with 2 abstentions) and that this should happen once the European Standard has been balloted. Such a development is in line with CEN practice and policy; more importantly it fulfils the goal set in the EC contract and articulated by the joint aspiration of *CEN IPS* and HL7 IPS to make the International Patient Summary applicable to a global market, as an ISO standard, of benefit to all.

### Dissemination:

The first objective of the EC Contract was to actively participate in regional and international activities that related to the exchange of Patient Summaries. Over the time of the project, the IPS teams have presented the IPS to many people at meetings, workshops and conferences. The primary purpose for doing so was to inform people about the work; it was also the intent of the project team to understand and learn from these audiences about how we might improve the outputs. To the extent that we were explaining and socialising the eventual standards, we were in fact undertaking a limited form of dissemination activity throughout the project's course.

We had come to realise during the project that, for it to succeed, the IPS should have the intended global impact; a corollary of this belief is the need for the IPS work to be able to reach multiple audiences, with different perspectives and pressures, if it is to achieve its potential. Furthermore, we realised that the majority of our stakeholders and beneficiaries would never even read the actual specifications!

This is a given for many of the individual citizens in need, of course, but it is equally true for the many politicians, policy makers, decision takers, managers and also non-technical folk who may have a role in getting the standards adopted and used! It is not just that a health informatics standard is often written in a techno-style that makes it impenetrable rather than in plain language, although sadly sometimes that is true. To some extent it is inevitable given the subject matter and the need to be concise, using known technical jargon as a short cut. However, there seems to be a growing awareness, as indicated by the eHAction Roadmap activity, and the recent ISO TC215 meeting in Sweden, that the SDOs need to do a much better job at communicating and disseminating material about what they do, how they do it, and about the standards they produce.

Report 31<sup>st</sup> May 2019

When the IPS project was presented there was usually a core message in every presentation with new bits around the side to make it more interesting. These side items, metaphors and some context, rarely make the pages of the published specification. Perhaps, dissemination could be made more economical if such material could be reused? In a bid to make the materials more accessible, not just in terms of content, but also in terms of time to read and in terms of relevance, several 'Prezi's have been produced that explain the IPS Standards in what we hope is a more digestible way. Prezi is an alternative to PowerPoint (although the PPT slides are still valuable and are available), but as Prezi enables the reader to use as much or as little as they need, as often as they require, without reading slides sequentially, it was decided to try this approach to help dissemination. It is, of course, not the only way; for example, *CEN IPS* is currently exploring the use of testimonials from countries already beginning to use the IPS for their national systems.

Dissemination is often a task left to the end of a project and often it is neglected as a consequence. This needs to change, perhaps across the board, but particularly with projects like the IPS; specifically, the facilitated discussion (Contribution 4) has reinforced the need for more effort to be put into collaboration, improving the communication and socialisation of the IPS.

The current Prezi presentations can be found here:

- CEN TC251 Project page: <http://bit.ly/IPS-Discover>
- *CEN IPS* dissemination: <http://bit.ly/IPS-Story>
- *CEN IPS* Info-Graphic: <http://bit.ly/IPS-iGraphic>

The first Prezi provides some context to the Project from a CEN perspective and then allows access to the IPS-Story. The second one is the IPS-Story that can be reached directly, if preferred. The third is like a single page poster of IPS (with the plus, that it permits zooming of content), which succinctly expresses the main IPS Concepts.

Sometimes, Prezi takes a while to launch but we hope, as with the IPS standards, that this brief wait is worthwhile!

## Contributions:

Organizer: Shirin Golyardi, CEN TC 251 Secretariat and *CEN IPS* Administrator

Chair: Robert Stegwee, CEN TC 251 Chair, Facilitated Contribution 4

*CEN IPS* Project Team:

Stephen Kay, CEN IPS Lead, Presented in Contributions 1, 3, and 5; Editor

Giorgio Cangioli, CEN IPS & HL7 IPS, Presented in Contribution 2

Karima Bouchard, CEN IPS, Presented in Contribution 3

Vincent van Pelt, CEN IPS, Presented in Contribution 3

eHAction Roadmap Leader D6.1: Christof Gessner, Presented in Contribution 3

Report 31<sup>st</sup> May 2019



Participants:



## Assignment of Exploitation Rights

Including the 'List of Participants'

Date(s) of meeting: 2019-03-19

Place of meeting: CEN-CENELEC meeting centre, Brussels

\* **CEN/TC251 Health informatics / IPS project final meeting**

**Secretary:** Shirin Golyardi

**NSB:** NEN

### Foreword \*\*

In order to secure the legal protection of the documents elaborated collectively by the participants (i.e. delegates of CEN Members and other experts in CEN's standardization work), you are asked to accept the following terms and conditions for the assignment of the exploitation rights of your contributions to European standardization by signing the list of participants. For convenience of use, this statement of assignment may also be used as the list of participants for meetings.

### EXPLOITATION RIGHTS ASSIGNMENT STATEMENT

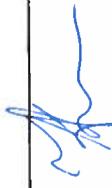
1. In the framework of the Berne Convention for the protection of literary and artistic works:
  - (a) By signing the attached list, I assign solely, exclusively and irrevocably to the European Committee for Standardization (CEN) for the benefit of its national Members the exploitation rights of my intellectual contributions, as are reproduced in the publications resulting from the technical deliverables of CEN, as defined in paragraph 1.2 of CEN/CENELEC Internal Regulations Part 2.
  - (b) I agree that CEN deliverables containing all or part of my contributions may be published without mention of my name.
  - (c) For the total duration provided for by law, I accept that exploitation will take place without mention of my name.
  - (d) I accept that this assignment does not preclude me from continuing to exploit my own copyrightable contribution for my own purposes, provided that such exploitation does not adversely affect the exploitation of the publications specified in (a) above.
2. Should I offer intellectual contributions for which I do not personally hold the copyright, I undertake to do the necessary to declare this to the appropriate CEN officer with regard to this Statement, or to any other relevant CEN body and to name the holder of the copyright if known to me, in view of securing the assignment of its exploitation rights to CEN.
3. The assigned exploitation rights are granted free of charge worldwide and cover all languages and all forms of exploitation known at present, in particular and non-restrictively: publication, reproduction and adaptation by all means and all graphical support systems, by print, press, photocopy, microfilms, and via all magnetic, electronic and numerical support systems, memory cards, CD-ROMs, DVDs, Blu-Rays, films, photographs, slides, teledistribution, cable, satellite, web applications and on-line document servers and networks, distribution, sub-distribution, translation, derive revenue from duplication, communication to the public in total or in part, in summary or with comments, transfers of exploitation licences to third parties.

---

\*\* The exploitation rights of contributions made by individuals from the UK government are covered by a separate agreement 'CEN/HMSO Licence Agreement' dated 26 July 2000.

## List of assignees

By signing this list of participants, I accept to assign the exploitation rights to CEN in accordance with the Exploitation Rights Assignment Statement

Name	Initials <sup>1</sup>	Signature	Date	Nominating organization <sup>2</sup>	Role <sup>3</sup>	Country	Employer <sup>4</sup>	Sponsor <sup>5</sup>
Stephen Kay	SK		17/3/19	CEN	IPS project leader	UK		
Giorgio Cangioli	GC		19/03/2019	CEN/HL7 international	IPS project member & HL7 IPS	IT		
Karima Bourquard	KB		19/03/2019	CEN/IHE	IPS project member	FR		
Vincent van Pelt				CEN/Nictiz	IPS project member	NL		
Robert Stegwee				CEN/TC 251 chair		NL		
Christof Gessner	Chg		19.3.19	eHealthAction	Task 6.1 leader	DE		
Jan Cap				National Health Information Centre	Division of Health Information and Services	SK		
Catherine Chronaki	CEC		19.3.2019	HL7 international	Technical coordinator Trillium II project	GR		

<sup>1</sup> Initials will be used in the meeting report

<sup>2</sup> Nominating organization = Name of the CEN Member (National Standards Body), Liaison organization, Partner organization, or other organization represented.

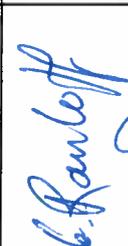
<sup>3</sup> Role = please indicate what you are representing i.e. delegate of a CEN Member (TC and SC meetings), expert appointed by a CEN Member (WG meetings), representative of an organization granted observership, Consultant, TC or SC Secretary, TC or SC Chair, WG Convenor, WG Secretary

<sup>4</sup> Employer = Organization of which the expert is an employee.

<sup>5</sup> Sponsor = Organization funding the expert in this standardization activity. If the sponsor is the same as the employer, please write 'SAME'.

### List of assignees

By signing this list of participants, I accept to assign the exploitation rights to CEN in accordance with the Exploitation Rights Assignment Statement

Name	Initials <sup>1</sup>	Signature	Date	Nominating organization <sup>2</sup>	Role <sup>3</sup>	Country	Employer <sup>4</sup>	Sponsor <sup>5</sup>
Antoine Chaudières			19/03	ASIP Santé	consultant	FR		
Angélica Cavalcante Galvão			19/03	ASIP Santé	Project manager	FR		
Andreas Klingler				Siemens Healthcare GmbH	Customer Services, Digital Services, Interoperability Competence Center	DE		
Thomas Penzel	T.P.		19.3.	Charite - Universitätsmedizin Berlin	DIN expert	DE	Charite	
Georg F. Ranhoff			19/3	Norwegian Directorate of eHealth	Department for Standardization	NO		
Reza Razavi				EC/DG CNECT	Policy officer	CNECT		
Pavol Rieger	<del>PR</del> PRI		19/3	Národné centrum zdravotníckych informácií Lazaretská 23	projektový manažér	SK	Národné centrum zdravotníckych informácií	
Eugenia Rinaldi	ER		19/3	BIH / CHARITE	CEI	DE		
Espen Stranger Seland			19/3	Norwegian Directorate of eHealth	Department for Standardization	NO		

## List of assignees

By signing this list of participants, I accept to assign the exploitation rights to CEN in accordance with the Exploitation Rights Assignment Statement

Name	Initials <sup>1</sup>	Signature	Date	Nominating organization <sup>2</sup>	Role <sup>3</sup>	Country	Employer <sup>4</sup>	Sponsor <sup>5</sup>
Ceri Thompson				DG CNECT, H3, "eHealth, Well-Being and Ageing"	Deputy Head of Unit			
Patrizia Tosetti				EC/DG SANTE	Policy Officer			
Heiko Zimmermann				Agence eSanté Luxembourg	Chief Digitalisation & Information Officer			
Natalia Zylinska-Puta			19.03.19	EC/DG SANTE	Policy Officer			
Alpo Värri (by remote access)				Tampere University of Technology	Associate Professor, CEN/TC 251/WG2 convener	FI		
Shirin Golyardi			19/03	NEN	CEN/TC 251 secretary	NL		
Vincent van Pelt			19-3-19	Nictiz				
Linus Karolius			19-3-19	Lithuania Health Ministry	E-Health advisor	LT		
JUAN PABLO MARTINEZ			19/03/2019	SPANISH HOA	E-HEALTH CONSULTANT	ES		

**List of assignees**

By signing this list of participants, I accept to assign the exploitation rights to CEN in accordance with the Exploitation Rights Assignment Statement

Name	Initials <sup>1</sup>	Signature	Date	Nominating organization <sup>2</sup>	Role <sup>3</sup>	Country	Employer <sup>4</sup>	Sponsor <sup>5</sup>
Lubov Gorbun			2019/03/19	Ministry of Health of the Republic of Lithuania	Chief Specialist	LT		
Maria Hassel			2019/03/19	Swedish eHealth agency	International coordinator, head of coordination unit	SE		
Rodube Alavi			2019/03/19	-	Senior advisor	SE		
PETER BRETER			19.3.2019	ELGA AUSTRIA	PM	AT		
LINDA HENSLY	LH.		2019/03/19	NSAF	STANDARDS OFFICER	IE		

