Patient Summary Standards Set Joint Initiative Council



Executive Summary

This is the first release of the Joint Initiative Council'S (JIC) Patient Summary Standards Set (PSSS). The intent is to provide guidance about health informatics standards, standards artefacts and profiles that meet agreed criteria, to meet a specific Use Case.

In April 2015, the <u>JIC</u>, a collaborative of 8 international digital health standards development organisations, discussed its strategic direction and agreed upon the following goal:

To better global patient health outcomes by providing strategic leadership in the specification of sets of implementable standards for health information sharing.

Charged with operationalizing this goal, the JIC identified the need to develop a number of relevant Use Case-focused Standards Sets. Standards Sets follow the working definition of "a coherent collection of standards and standards artefacts that support a specific use case." These use cases and accompanying recommendations are developed for national and international use.

The first Standards Set the JIC prioritized for development was the 'Patient Summary', given the interest in this topic globally and applicability across JIC membership. Of utmost importance to its development is that PSSS has been built on existing standards that leverage the wealth of knowledge and expertise available within the health information standards environment.

A Standards Set does not recommend a single, specific implementation for a particular use case. Rather, the intent is to provide sufficient detail to enable the different stakeholders to follow a process to enable them to identify the standards, standards artefacts and profiles most suited to satisfying their requirements. Whilst this first Standards Set is focused on the 'Patient Summary', the long term aim is to take this exemplar and lessons learned to develop generic guidance which can be applied to other Use Cases.

The Standards Set guidance document is meant for a wide audience – clinicians who use patient summaries, implementers who deploy, software developers who build the tools and systems, experts who work in the fields that touch health and standards, and most importantly, governance bodies that make decisions to fund new digital deployments. The Patient Summary Standards Set guidance document is free and is meant to be informative, not normative.

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The PSSS is comprised of 4 key aspects:

- 1. Use Case for the Patient Summary. After analysis, it was decided to apply the Use Case as described in ISO TR: 19669: 2017 and focused on a patient with Chronic Obstructive Pulmonary Disease attending an Emergency Department when away from home. An accompanying dataset was produced.
- Categorisation, analysis and selection of standards, artefacts and profiles. A methodology was drafted and documented in <u>'Standards Categorization for identifying and analysing the</u> <u>Standards in a Standards Set</u>'. This was then applied to the Use Case as described to identify appropriate standards, artefacts and profiles.
- 3. **Conformity assessment.** A framework was developed based on what is currently used in the healthcare industry and suggestions made as to how this could be used for the PSSS, given that it is not a fixed set and that standards individually have conformance criteria and the users have choice.
- 4. **Information sheets as guidance for implementation.** Each standard will have its own guidance so the focus of these information sheets is on providing guidance within the implementation context and are based on current practice.

Each aspect of this work has been led by a JIC member who has recruited the input of subject matter experts from across the globe. Together they have worked jointly on the methodology followed by application to this first Use Case. Early thinking can be found in the *'JIC Foundation and Scope Report _ October 2015'*. Following development of the methodology, JIC members engaged in additional review prior to extending the Standards Set for review by stakeholders identified in the community.

The PSSS is subject to the changing landscape in health and will be regularly updated based on user feedback to take into account the changing/evolving nature standards and related products. This first version is, therefore, based on standards, artefacts and profiles as of January 2018.

The JIC wants users to provide feedback so that this document can move in tandem with the developing needs of a patient summary, evolving and changing standards and experience of use. To facilitate this feedback mechanism, a standardized form along with submission guidance can be accessed through the Joint Initiative Council's <u>dedicated PSSS webpage</u> and by directing feedback to <u>psssfeedback@snomed.org</u>.