Report International Patient Summary Workshop

Bridging projects & Initiatives

"Think of the patient summary as a window to a person's medical history and health data with links to more detailed information."

On 7 February 2017, the European Commission (the eHealth, Wellbeing and Aging Unit, DG Connect) hosted a concertation workshop of European projects and initiatives related to the International Patient Summary - policy, deployment, competencies, and standards.

The participants received the Patient Summary data set of the latest European Patient Summary Guideline endorsed by the 10th meeting of the eHealth Network on November 23, 2016.

Policy officer Gerald Cultot, DG Connect, welcomed the 35 experts from 15 states in Europe, the United States and China. Highlighting the importance of the data economy, he invited participants to respond to the Public Consultation on Building the European data economy, open until the 26th of April 2017, considering data access, portability, and free flow of data.

Then he introduced five questions to be addressed by the workshop:

a) What is the current landscape of patient summaries in Europe and beyond?

b) What is the vision for where we should go next?

c) How do we bridge the gap between what we have and what want to achieve?

d) Who are the stakeholders that need to be on the table?

e) What are the next actions?

Patient at the center

Henrique Martins, President of the eHealth competence center of the Ministry of Health in Portugal, inspired the participants with his opening speech entitled "Digital Patient Summary in the Wallet: Bridging the gap from strategic intent to social impact".

Observing that today health data are dispersed, with national or regional government-led electronic health record projects and ad hoc personal health records controlled by the patient, Henrique stressed that we need to bring the pieces together. We need to place the patient at the center allowing the addition of personal 'stuff'; 'my Patient summary data' next to the health professionals' data.

The Portuguese approach - My SNS Carteira (stands for 'patient summary in your pocket') - focuses on portability and tailorability so that patients control and can move their own data.

1 These projects and initiatives are eStandards, VALUeHEALTH, EU-US eHealth at Work, EURACARE, Trillium Bridge II, and JAseHN
In the end, we can live with some ambiguity, Henrique points out: "Let the patients help build their own patient summaries so that it makes sense to them, rather than aim for an elusive complete picture of a person's health."

Diverse patient summary implementation landscape

After a brief introduction of the updated European Patient Summary Guideline, patient summary initiatives from France, Luxemburg, Croatia, Austria, Catalonia, Germany, Norway, Denmark, and the United States painted a quite diverse patient summary implementation landscape. There were notable differences in the scope, structure, assembly, validation, and frequency of update for patient summaries.

The ability of patients to access and actively contribute to the patient summary, although accepted and mandated, is not there yet. But as a clear trend, more and more health apps provide specialized views, windows to a persons' health data.

Jamie Ferguson, speaking for Kaiser Permanente in the United States, noted a shift from integrating the data to sharing data through dedicated interfaces in ways that focus on usability and engagement.

Representatives of national physician associations in Austria and Norway stressed the need for usability and automatic assembly of the patient summary to reduce physician workload.

Emergency care, planned care, cooperative care and self-care

Following a demonstration of apps implementing notions of the patient summary in various contexts, in a working lunch, breakout groups discussed extending the use of patient summaries beyond unscheduled or unplanned care to address the needs of emergency care, planned care, cooperative care, and self-care.

Luc Nicolas (JAseHN project) asked how we get to the patient summary data and how we gain value, who provides information and who controls it? Who is using it and for what purpose? Michele Thonnet (VALUEHEALTH) pointed out that we move away for centralized management of data to a new way, in part controlled by the patient. How can we make this work? With business models or laws? Laws take time, while business models shared by all stakeholders can be a good starting point.

Ting Shi (Leiden University Clinic) notes that the patient summary needs to be self-motivating to the patient and offer interim results of self-care. However, people are not the same and their motivations are different. Harm-Bastian Harms (European Assistance team for Citizens in Areas of Evacuation EURACARE) requested that we focus on solutions to real problems. We need to make the data available where needed.

Rachelle Blake (EU-US eHealth at Work lead) highlighted the need for measurable, achievable competencies to ensure that we have mechanisms to contribute to a skilled healthcare workforce, supporting integration of the patient summary in eHealth work throughout the European Union and globally.
Patient summary standardisation initiatives

In the next session, patient summary standardisation initiatives, Catherine Chronaki, explained the vision of the digital health compass in eStandards that builds on cooperative standards development to address the needs of health systems, consumers, the workforce, and the eHealth Market.

Then, Robert Hausam (US ONC, HL7 IPS project lead) reported on the principles agreed in Oslo, by the HL7 and CEN TC251 IPS project teams to create a single common International Patient Summary (IPS) standard that is implementable, global, sustainable, extensible and open.

Giorgio Cangioli (CEN TC251 IPS project team, HL7 IPS co-lead) reported on the standardization progress highlighting the complementary nature of the project, aiming in the near term to a minimal and non-exhaustive patient summary that is specialty agnostic, condition-independent but readily usable and extensible by clinicians.

Stephen Kay (CEN TC251 IPS Project lead) revisited the metaphor of the patient summary as a window to a patients' health data, saying that "the window has to be positioned, resized and fit for purpose so that it can pick out all of the relevant bits of the patient data, not just one narrow aspect. If the patient summary is the eyes, then standardization is helping frame and focus the picture." He moved on to underline that "the international patient summary has to be focused, otherwise it won't be useful. For that to happen, agreement on the data needs to be reached. How data will be transported is a secondary issue."

Need for shared vision

The closing discussion acknowledged once again the fragmented landscape and the need of a shared vision to focus our efforts.

Joan Dzenowagis (World Health Organisation Geneva), reaffirmed the interest of WHO to explore the patient summary as a social good, and proposed the formation of a task force to move us forward.

Gerald Cultot (DG Connect) closed the session noting that workshop was timely and necessary and suggested a follow-up within the next six months. A white paper under preparation will capture the results of the meeting.

Presentations are available here.

Agenda of the event