



## INFORMATION PAPER

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### Intermediate Proposal for Initiating a Platform Consisting of the Standards Developing and Profiling Organizations Relevant to eHealth in Europe and Members of the eHealth Network Joint Action

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<b>Author(s):</b>	<p>Merik Seven, Nictiz (Netherlands) Michiel Sprenger, Nictiz (Netherlands)</p>
<b>Member State Contributor(s):</b>	Nictiz (Netherlands), GEMATIK (Germany), FRNA (France), 3DHHR (Greece), BBU (Romania), ASIP (France), THL (Finland) and HDIR (Norway).
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## 1. Purpose

This deliverable is the follow-up of topic 6 on the agenda of the 7<sup>th</sup> eHN meeting. In this 7<sup>th</sup> eHN meeting it was decided to proceed with the presented proposal for initiating a platform consisting of the standards developing and profiling organizations relevant to eHealth in Europe and a representation of the members of the eHealth Network Joint Action. This paper reflects the interim outcome of this process and should be seen as an adjusted proposal, to be discussed in the 8<sup>th</sup> meeting of the eHN, to bring the process forward for decision towards final and formal installation of the collaboration platform in June 2016 (9<sup>th</sup> eHN meeting).

This proposal introduces the introduction of an intermediate step in the process of initiating such a collaboration platform. This intermediate step was deemed necessary after consultation with the quartermasters of the foreseen platform. The complex task and limited preparation time has led to the insight that more time spent to elaborate on the scope and objective of the collaboration platform will lead to better utilization of the broad support, that has indeed been expressed, for the platform. Compared to the proposal which was discussed in the last eHN meeting (May 2015) this adjusted proposal reflects the broader opinion of the targeted platform members.

The proposed intermediate step will initiate a collaboration platform under construction for standards developing and profiling organisations (shortly here SDOs) and a representation of National Competence Centres (NCCs). During the formation phase this platform will gradually start to function as a one-stop shop for the eHN and JAseHN regarding strategic and more practical issues of eHealth standards and profiles development and support of deployment. This intermediate step will have 2 objectives for the next 6 months:

- 1) Settlement of current and upcoming eHealth standards and profiles development and support of deployment issues / questions, etc.
- 2) Establishment of a founding document (terms of reference) for the more permanent phase.

In order to stimulate the establishment of the collaboration platform the usage of the platform under construction should be encouraged (learning by doing). During the next 6 months, the newly formed platform can be used for current and upcoming standards and profiles development and support of deployment businesses (e.g. piloting a joined process through the specification of the European Patient Summary Standards Set, alignment with the proceedings of the Rolling Plan) and for alignment on activities with JAseHN Work package 4 (stakeholder liaisons).

## 2. Status

### 2.1 Activities undertaken so far towards the proposal for a SDO platform

In the procedure towards the establishment of an SDO platform, originally planned for decision in the 8<sup>th</sup> eHN in November 2015, the following steps were taken:

- A face to face (F2F) meeting in The Hague on September 1st, 2015, with all members of task group 5.4 invited. Present were: THL (FI), ASIP (FR), HDIR (NO), Nictiz (NL), GEMATIK (DE) and 3DHRR (GR). Robert Stegwee and

Jeremy Thorp were asked, on a personal basis, to give their broad perspective on eHealth standardization, worldwide and European, in order to start the discussions. Manne Andersson was present as an observer from WP5 leadership.

- A F2F meeting in Brussels on September 9th with European level representatives of the selected starting group of 6 SDOs: CEN/TC 251, Continua Health Alliance (CHA), GS1, HL7, IHE and IHTSDO. The members of the task group present were: ASIP (FR), FRNA (FR), GEMATIK (DE) and Nictiz (NL).
- A teleconference meeting with the same group invited as the F2F of the 9th, on September 16th.

Topic of the meetings was the discussion paper on the SDO platform, presented in the 7th eHN in May, 2015. During the F2F with the SDOs in Brussels it was decided to elaborate the core characteristics of the platform by following the lifecycle for standards and solutions, in two phases: development phase (with the steps developing base standards, harmonization, profiles, assurance and testing) and interfacing with the deployment phase (with the steps implementation, monitoring and review, feedback and maintenance).

The following can be stated from the actions and discussions:

- All participants agree that it is a very wise idea to establish such a platform;
- All participants agree that the platform should consist of the SDOs (including profiling organizations) and a selection of NCCs, with critical notes and questions like:
  - What is an SDO, which organizations should be eligible in the future?
  - Idem for NCCs, plus:
  - Which selection of or interested NCCs and what is their role towards the eHN members, other NCCs, etc.
- All participants agree that the platform should be a discussion partner for eHN and JAseHN.
- All participants agree that the platform should liaise with other relevant parties outside Europe (JIC, ISO, ...) and outside eHealth (MSP, eHSG, ...).
- The discussions were fruitful but not yet conclusive on the general scope of the platform. There was constructive criticism on the discussion paper on at least:
  - The platform position around development of base standards
  - The policy level influencing by the platform
  - The deployment of solutions based upon standards

Although scope items like “supporting”, “informing”, “explaining”, were found quite eligible for activities of the platform.

- The discussions were very productive but not yet conclusive on governance issues. The most important issue was maybe the agenda setting. One of the basic tasks of the platform is felt to be “avoiding gaps and overlaps”, however, for avoiding gaps there should be:
  - a route from the platform towards the development agenda of the individual SDOs There were strong statements that this route was driven

- by SDO membership and would be a challenge for some of the SDOs, while others could manage it.
- a route towards the deployment agenda of the NCCs and eHealth projects across Europe.
- All parties however agree, that the platform should start, and then maybe in a “learning by doing” mode. So, start with limited scope and doubts on governance possibilities, but start working and come with a more final proposal towards eHN in a later stage. The differences found in the opinions should be seen as a means and resource to eHN of expressing a deeper understanding of the problems that beset the standardization landscape.

With reflection to the limited preparation time for the 8th eHN meeting combined with the apparent complexity of the task, whilst observing broad support for such a platform it was proposed to introduce an intermediate step towards final shaping and installation of the collaboration platform. The eHN will be asked to support this intermediate step and to simulate the discussions and the elaboration process.

## **2.2 Initial scope of the platform for the next 6 months**

The Joint Action to support the eHealth Network (JAseHN) is the basis for establishing a collaborative SDO platform, comprising the main Standardisation bodies in eHealth together with the Competency Centres of the eHN Member States. The platform will act as a reliable focal point (one-stop shop) for technical and semantic eHealth standards and profiles development and deployment support that will strive for maximum alignment and mutual significant influence between the policy (demand) and operational (supply) level.

The collaboration platform will have 4 main objectives in the first half year:

1. To provide relevant technical and semantic expertise and information to support eHN policy (e.g. for guidelines on patient summaries across Europe) and to align understanding of the domain’s complexity between the members of the platform and eHN.
2. To provide guidance on the specifications required to satisfy an EU eHealth requirement (there may be conflicts, overlaps and gaps in current provision that need to be managed by a concerted effort of the parties involved). A direct engagement of the National Competence Centres (NCCs) in identifying such gaps is critical.
3. To draw support from the standards developing and profiling organizations in favour of the implementation of their standards and profiles in the context of EU requirements or guidelines.
4. To function as a liaison with global, national and other EU standardization initiatives

In the intermediate stage the SDO platform should concentrate on delivering value by focusing on a small set of deliverables that are both achievable and assessable to benefit eHN and the countries they represent. The output of the platform should aim for increased eHealth interoperability, which will require collaboration to make coherent, harmonized and validated solutions possible. After agreeing scope and objectives, the first task, of paramount importance, is to establish a governance structure which is open, transparent and operates by consensus.

The proposal to form SDO platform finds its rationale in “The case for formal standardization on large-scale eHealth deployment “(annex 1). It will therefore also closely cooperate with the global collaboration initiative between SDOs (Joint Initiative on SDO Global Health Informatics Standardization). In principle the SDO platform and the Joint Initiative are built on a mutual foundation. To enable common, timely health informatics standards by addressing and resolving issues of gaps, overlaps, and counterproductive standardization efforts.

The proposal to form SDO platform adds additional value to the Global collaboration initiative by:

- Being an European collaboration platform for eHealth standards and profiles development and support of deployment of cross border information exchange in healthcare.
- Being a collaborative platform for all relevant SDOs, profiling organizations and National Competence Centres which have an important complementary role in eHealth standards and profiles development and deployment support on a National level.
- Being the primary interlocutor for the strategic policy level representing the demand party for EU eHealth standards and profiles development and deployment support.

### **2.3 Approach to getting the platform established**

1. Scope and objectives for the collaborative platform to be adopted by key participants, including financing, the decision making processes and the expected life-cycle of the SDO platform.
2. Piloting a joint process through the specification of the European Patient Summary Standards Set. Note, the joint process itself should not be run from the platform, it should be initiated and monitored as part of its guiding role).
3. Crafting the responsibilities outlined for the development phase alongside the execution of the joint process.
4. Crafting the responsibilities outlined for the deployment phase alongside the actual implementation of the first standards sets.
5. Growing up (maturity): assessing the services and contact points for other initiatives, including EC projects, NCC demands/initiatives and local SDO chapters.
6. Delivering a final proposal for formal installation of the collaboration platform for the 9th eHN meeting in June 2016.
7. During the next 6 months the platform under construction will pilot its intended function as a one stop shop for the eHN and the strategic EU policy level regarding (strategic) standards and profiles development and support of deployment items.

It is suggested that the task of the proposed action plan towards final installation will be conducted by the current JAsHN task members of D5.4.1 as a representation of the NCCs and a core group of relevant SDOs (current SDO group).

## 2.4 Conditions for success

The current process, which has produced an intermediate proposal rather than a final document for eHN, has clearly demonstrated how difficult it is to produce something in a short time-scale with all the existing constraints on the key parties. The proposed approach for setting up a collaboration platform must be realistic and pragmatic to be successful. However, the proposed ‘platform under construction’ according to the present paper will need to continue the on-going discussions, learn by doing, and provide services and deliverables to eHN.

To be able to be successful in achieving the objective of installing a collaboration platform the following items are seen as preconditions:

1. A solidary solution for the lack of allocated “platform” resources of Standards Developing and Profiling organizations. Most SDOs and Profiling organization are driven by members that participate voluntarily and in kind. The work in the platform will certainly require travel costs, communication costs next to hours.
2. A consistent and coherent use and approach of the SDO platform by the eHN for all issues related to eHealth standards and profiles development and deployment support during the next 6 months.
3. Positioning of the SDO platform as the dominant way for the SDOs to influence the EU eHealth policy level.
4. A general solution for the expected lack of influence of the board of some of the Standards Developing and Profiling organizations on their own development roadmap. The strategies of the SDOs and Profiling organizations and/or local SDO chapters are mainly organized bottom up. This dominant strategy approach undermines the ambition and ability to prioritize the workload from top to down in order to avoid gaps and overlaps between the different base standards.

The members of the eHN are asked to take a position on this success conditions and the role and responsibility that it is provided for eHN:

- The first precondition is the most important one and requires further investigation of the issue in parallel and in alignment with the SDO platform under construction. The eHN members are asked to recognize the relevance of this issue, to support and initiate further investigation and to jointly work with the SDOs on a solidary solution for all parties involved.
- The second and third precondition are under the direct influence of the eHN and need to be decided upon by the eHN members.
- The last precondition is an issue that should be addressed jointly by the SDOs and JASEHN to ensure stakeholder alignment and the success of the SDO platform. This precondition is the least important for the next 6 months. The eHN members are asked to recognize and carry out the importance of this success factor for realizing the main objectives of the SDO platform.