Annexes to the Trillium Bridge Policy Convergence Recommendations

Contents:

Appendix 1: Elaboration of the topics leading to the recommendations

1 Introduction

This Appendix supplements the policy convergence recommendations of Trillium Bridge, published in Deliverable 5.2, by summarising the context and method by which they were produced and elaborating the issues and approaches that were explored during the project that led to the recommendations.

2 Context

It is recognised that it is challenging to deliver safe and effective care to patients presented to a general practitioner or emergency department in a situation where there is no background health information on the patient. Medical summaries, sometimes given to patients to carry on paper when they travel, and at other times sent urgently by fax, have long been used as a method of quickly informing an emergency care provider of the salient facts to enable them to make safe and optimal decisions. On the other hand, many unscheduled care encounters are handled in the absence of any such summary information, and many healthcare providers are used to dealing with clinical situations where they have to infer all that they need to know, including scenarios in which a patient is unconscious or unable to give a clear account, and where there is no relative or other carer to provide this information.

Clinically led developments of standardised medical summary specifications have been published over many years, in different countries and by different specialties, one widely known being the ASTM Continuity of Care Record (CCR)[1] based on earlier work of the Massachusetts Medical Society. The CCR is a generic medical summary intended to convey salient information when handing over the care of a patient from one organisation to another, such as when a patient is discharged from hospital.

HL7 jointly with ASTM developed HL7 CCD [2], a Clinical Document Architecture (CDA) implementation guide for CCR that can be exchanged as electronic messages. Later on, Standards Developing Organizations (SDOs) namely IHE, HL7, HealthStory collaborated to align implementation guides for seven clinical documents types, CCD being one of them. This effort resulted in the so called Consolidated CDA (CCDA). HL7 CCDA CCD is referenced in United States Meaningful Use program certification criteria as the means to achieve continuity of care and patient empowerment. Patients may receive their CCD after the visit to the general practitioner. Physicians may send the CCD as part of a referral request. There have been subsequent somewhat divergent activities in EU to formalise the representation of an emergency care summary that can be used to inform an unscheduled clinical encounter. These activities include the incorporation of CCD in IHE projects, most notable among the ePSOS patient summary service that formed the basis of the European Union Patient Summary Specification and the work of HealtheWay and other eHealth exchanges in the United States.

Recognising the value in transatlantic collaboration to support emergency care scenarios when European patients travel to the US and vice versa, the Trillium Bridge project has brought together informatics experts and representatives from key standards bodies to compare specifications and

[1] ASTM E2369 – 12 Standard Specification for Continuity of Care Record (CCR), 2012. DOI: 10.1520/E2369-12
[2] http://www.hl7.org/implement/standards/product_brief.cfm?product_id=6

samples, to create bridging translations between these summary specifications, and establish the common baseline.

Recognising the value in transatlantic collaboration to support emergency or unplanned care scenarios when European patients travel to the US and vice versa setting an precedent for global cooperation, the Trillium Bridge project assembled a broad transatlantic community of collaboration and knowledge sharing, for eHealth stakeholders including key standards bodies to compare specifications and samples, to create bridging transformations, and to establish the common baseline for an international patient summary. That work has been reported in project deliverables from the packages 2, 3 and 4, which addressed gap analysis, interoperability assets, testing and validation of transforming EU patient summaries developed under epSOS with clinical summaries delivered as part of BlueButton+ or the Meaningful Use stage II program.

Work package 5 taking into account the evidence collected in WP 2, 3, 4, takes a step back, to reflect on the actions that need to be taken so that an International Patient Summary standard be implemented by the vendors of EHR systems and other eHealth infrastructure components and services to advance global interoperability.

WP5 basically ask the question "*What else is needed in order for this transformational transatlantic bridging work to be the basis for an international patient summary standard, widely adopted and incorporated into products, deployed across Europe and the US, successfully used by healthcare organisations to generate meaningful patient summaries, for receiving healthcare providers to trust and make good use of that summary information, and for all stakeholders to be comfortable with the protections in place over these information flows*."

Looking to the future, this work package has also asked "*What are the implications of the lessons learned in Trillium Bridge and the experience of developing standards for patient summaries, for the future of health informatics standardisation, and what are the future areas of research that still need to be explored."*

3 Approach

The work package has developed recommendations for policy convergence between the US and the EU to facilitate the adoption of an international Patient Summary Standard. Seven key topics were identified as being the most important areas in which specific enabling initiatives are needed:

- Education
- Innovation
- Incentives
- Future standardisation
- Cross vendor integration
- Privacy and security
- Research

This report summarizes the outcome of expert consultations on the principal challenges that may need to be addressed under these seven topic areas, and some candidate approaches are proposed. The more detailed results of these consultations were reported in Trillium Bridge Deliverable 5.1, and the approach that has led to the final policy convergence recommendations is summarised briefly below, and shown in Figure 1.

A set of challenges under each of the seven topics was drafted during the first year of the project starting with the collection of patient stories. Through an online consultation a matrix of experts was constructed, mapped to the seven topic areas, and used for initial waves of e-consultation to brainstorm the most important challenge areas and potential success strategies for each topic. An

online questionnaire survey was conducted during November 2014 and communicated to the 64+ experts that comprise the wider transatlantic community in Trillium Bridge. These are people initially invited as experts, as well as individuals or organizations that provided a subsequent expression of interest in the project. Among the questions asked were recommendations for additional people that should be approached in the Trillium Bridge efforts to further unpack and prioritize the issues, who then became part of a wider consultation network.

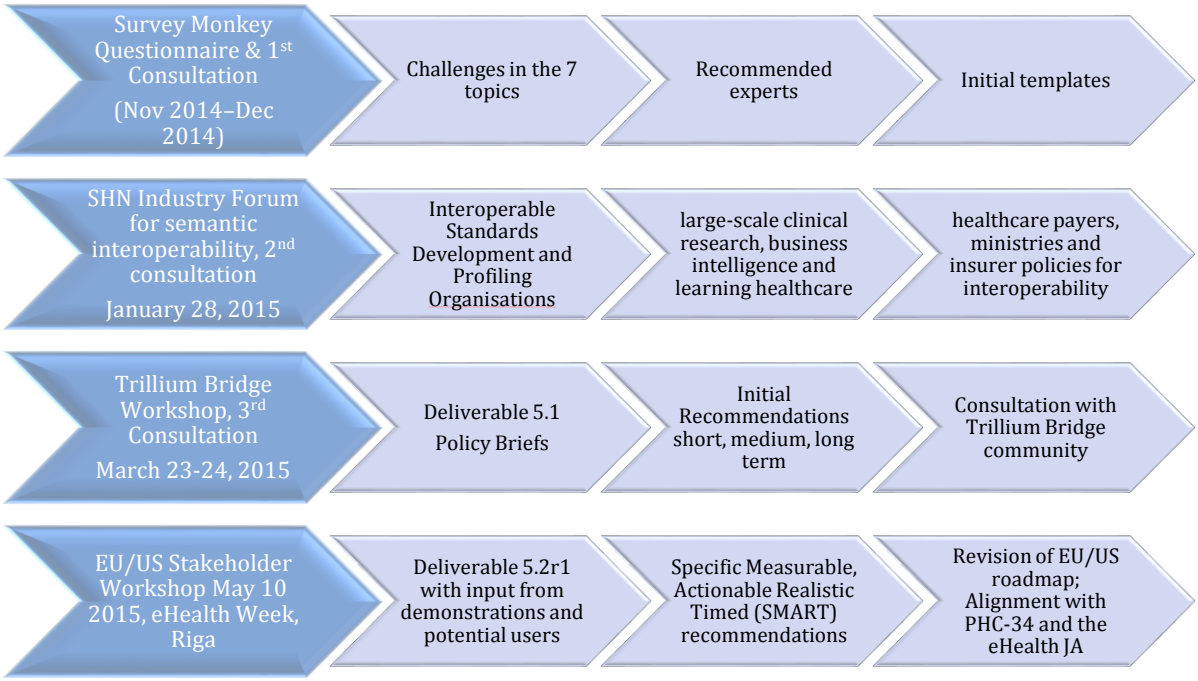


Figure 1: Approach to developing the Trillium Bridge recommendations

A template was constructed and progressively populated through e-consultations during the winter of 2014. The initial templates, along with the outcomes of rich interaction at the SemanticHealthNet Industry Forum at the end of January 2015, were used to guide the intensive discussions during the transatlantic workshop held on 23rd and 24th March, in Brussels. 28 experts (including EC Officials) participated in a mixture of plenary and breakout group sessions.

Further details of the approach taken during Workpackage 5, the details of the March 2015 workshop, the populated templates and the details of the initial e-discussions are all reported in Deliverable 5.1. Arising out of the March workshop results, supplemented by further rounds of e-consultation, a set of recommended actions were proposed for future EU-US cooperation. These recommended actions were presented and discussed at a final project workshop held during eHealth week conference in Riga, in May 2015. The definitive recommendations published in the body of this deliverable reflect the outcomes of those discussions and further post-conference consultation with the Trillium Bridge experts.

Following the May workshop the recommendations were shared and discussed in different fora including CEN TC251 management committee, HL7 International Council and the Joint Initiative Council for global Health informatics standardization, in an effort to receive broad support for the recommendations and associated action plan presented in the Appendix. At the time of this writing several organizations have endorsed or are in the process of endorsing the key recommendations of Trillium Bridge. The draft action plan will be handed off to the Joint Action supporting the eHealth Network, the ONC, and the four PHC34 projects i.e. ASSESS CT, ValueHealth, eStandards, and

OpenMedicine. The rest of this Annex summarises the issues explored and approaches proposed for each of the seven topic areas, as elaborations on the recommendations.

4 Summary of findings for the seven topic areas

4.1 Challenges and strategic objectives

4.1.1 Future standardization

A standard for an international Patient (health) Summary will need to interface with many other health informatics specifications and standards, and it will therefore be vital to engage standards development communities in adopting the patient summary as a standard, and interfacing it with other relevant standards. One of the key problems is that standards have traditionally been developed in silos, within individual SDOs, whereas patient summary communication, and other similar flows needed in the future will have to use multiple standards together. The Joint Initiative on SDO Global Health Informatics Standardization has enabled some degree of mutual awareness of forthcoming standards across SDOs, cross-balloting of them if relevant, and work is in progress to allow standards from other SDOs to be incorporated by ISO by reference. However, the SDOs need to better enable the easy and reliable bundling of multiple SDO standards that will need to be used together to deliver specific interoperability solutions. This topic has considered how to engage SDOs in adopting the International Patient Summary as a global standard and interfacing it with other relevant standards, and supported by quality assured interoperability assets. It has also considered how standards could be better promoted by health ICT policy makers and decision makers and the industry. There is hope that the recent San Francisco declaration of the JIC will pave the way towards such developments.

Figure 2: JIC San Francisco declaration of April 19, 2015

A cross-border, transatlantic, and ultimately global, market in interoperable services for handling and communicating Patient Summaries will require many (technical, semantic and security) standards. Despite being developed and published by different SDOs, the portfolio of standards needed to deliver a wide-scale and acceptable solution must be capable of being implemented together by different vendors in reliable and consistent ways. Industry (and downstream end users) must be able to judge and trust that these standards have been developed to a high quality. SDOs will therefore need to collaborate to deliver "joined up" standards that are of high quality and are maintained in synchrony. This will additionally require consensus on transparent standards maintenance processes and the governance of this.

The development of standards is not always a clear response to well documented requirements, and targeted to enable a particular and well delineated functional (interoperable) capability. Scope creep often occurs, sometimes resulting in standards that might meet multiple use cases, but are too complex or abstract for any one of them, and/or which overlap in scope with other standards. This can easily result in vendor confusion about when and how to use each standard, variability in how complex standards are implemented, and is an inhibitory factor to the overall uptake of standards by the health ICT sector.

The adoption of standards can be more expensive than in-house proprietary approaches to implementing the same function, especially if conformance testing is part of that adoption process. Conformance to standards needs to be included within procurement specifications, and standards need to be used within nationally or regionally procured platforms and services.

Strategic objectives:

- Engage SDOs in adopting the patient summary as a global standard and interfacing it with other relevant standards supported by interoperability assets
- Standards must target clearly defined purposes and interoperability use cases, and meet clearly specified user requirements
- Standards need to be actively promoted by health ICT policy makers and decision makers and the industry

Relevant Recommendations:

Standards and profile development organizations and eHealth/health IT stakeholders should by 2020:

1. collaborate on developing and adopting an IPS standard to enable the interoperable representation and communication of information about a patient's immunizations, allergies, medications, clinical problems, past operations and implants, building on reusable interoperability assets and tools;
2. work closely with clinician and patient associations in the EU, US, and globally to define, refine, and validate the IPS standard, and establish with them a standing governance process under the Joint Initiative Council of SDO Global Health Informatics Standardization to maintain it in the light of updated requirements, legislation and learning from use of the IPS;
3. target the IPS standard as the means for sharing a core set of clinical data for the purpose of emergency or unplanned patient care, aligning it with other relevant existing standards, and incorporating where possible the needs of public health and other secondary uses of aggregated health summary data;
4. work with producers of multi-national terminology systems to publish reliable and quality assured translations of patient summary value sets between relevant languages and of cross-mappings between terminology systems;
5. work with EU and US policymakers to secure funding for governance processes to validate and endorse the accuracy of cross-border clinical information structures and associated terminology value sets.

4.1.2 Cross-vendor integration

This topic explored the cross-vendor alignment of terminologies and data structures, initially through mappings, that enable each vendor to generate and export a valid International Patient Summary, to import and combine summary data coming from other systems. This includes strengthening the role of conformity assessment.

Health summary information is represented differently in different EHR systems, and offer users different capabilities for creating and using summary information, including linking this to other parts of a patient's EHR. Vendors will need to be able to import and export patient data according to the Patient Summary specification, and to develop methods of allowing clinicians to see imported data alongside locally held data (for example, an integrated medication record) whilst differentiating the imported data for medico-legal purposes. Given the wide deployment of legacy systems, conformance to the International Patient Summary Standard needs to have been validated using robust high quality tools and rich test datasets based realistic legacy data. This may include mapping locally coded data (or even non-coded data) to the terms used within the interoperable summary. Vendors will need to consider, and probably to collaborate with other app developers, to enable patient access to health summary information.

Strategic objectives:

- Enable every EHR system vendor to generate and export a valid summary, and appropriately combine summaries with other data.

Recommendations

EU and US policy makers in collaboration with competence centres and other relevant stakeholders should:

- promote the capability to generate and export patient summaries in the IPS standard, as well as import and integrate patient summaries in the IPS standard with locally-held EHR data;
- advance conformity assessment methods and tools that verify the robustness and quality of vendor implementations of the IPS standard, including the ability to generate and exchange patient summaries conforming to the IPS standard from / between EHR systems.

4.1.3 Innovation

This topic area considered how best to stimulate a vibrant market in applications that capture and deliver Patient Summaries that are meaningful and useful to care providers and meaningful to patients e.g. mobile device apps. There are presently some perverse incentives, and disincentives, to establishing business models for scaling up the exchange of summaries. Hosting the infrastructure to communicate patient summaries across borders is expensive to establish and maintain, including the various governance and translation services. The sender of an international patient summary is not responsible for the care required urgently elsewhere, or its costs. The receiver of the international patient summary will get paid for delivering care, and might actually be paid more for performing tests that duplicate recently performed tests. Cross border services are presently most used by business travellers and holidaymakers, not the most ill or elderly.

Vendors need to perceive a market that justifies their investments in implementing the International Patient Summary Standard, and applications for clinicians and for patients that enable the easy curation of Patient Summaries, and support views of communicated patient summaries in this standard that aid safe and effective decision making. This market will be driven by procurements within the health sector and by consumer purchases. This in turn needs to be stimulated by value demonstration from early adopters possibly driving on the mHealth apps adoption. It will need to be a global market, underpinned by global standards, and motivated by a hunger for comprehensive, ready-to-use, patient-specific information and patient-relevant knowledge.

Strategic objectives:

- Stimulation of a market supporting the patient summary in applications that capture and deliver patient summaries, evolving novel products, software as service packages and novel business models and opening up new markets and customers for differently thinking entrepreneurs.

Recommendations:

EU and US policy makers, and eHealth/health IT purchasers and providers, with support from relevant stakeholders, should:

- stimulate the market for the adoption of the IPS standard by lowering trade barriers and supporting entrepreneurs working with eHealth/health IT systems and mHealth applications to capture and deliver patient summaries in the IPS standard, and by encouraging novel business models;
- make a joint transatlantic commitment to demonstrate the value of sharing patient summaries in the IPS standard internationally, potentially leveraging events of high visibility such as international sporting championships;
- refine, test, and evaluate multiple models of comprehensive person-centred health information stewardship, supporting the IPS standard.

4.1.4 Education

Innovations introduced with the international patient summary standard must be backed up by adequate investments in workforce education. This topic area considered how to foster the development of training for all health professional disciplines and specialties who will create or use data items that are contributing to the Patient Summary, so that they use terms and information structures consistently and will make best use of summary data coming from other provider systems. This includes promoting the development of guidance and training for all health professional disciplines and specialties, and patients, about the creation, maintenance and use of good quality health record documentation, and helping clinicians to understand the extent of reliance they should place on health information received through a transatlantic summary from another country.

There is variable practice in creating, and especially in maintaining the clinical documentation within EHR systems that is needed to generate patient summaries, such as maintaining up to date problem lists, partly because of differing perceptions of how valuable such summaries are to colleagues. There is limited consensus on what levels of problem severity and detail should be included, which acute or short-term events to include, if non-medical health factors belong in summaries. There is poor guidance or consensus on when items should be removed from a summary or declared inactive, and summaries therefore tend to accumulate content rather than being carefully curated. This is especially a risk if patient summaries are generated automatically rather than manually curated. Different specialities have different concerns, and therefore value different kinds of content in a patient summary - and are not always good at considering future users from other professions and care settings. Few professionals have experience of sharing patient summaries with patients, and vice versa.

Clinicians have a tendency to not trust information “not collected here”, and they re-take histories, duplicate tests etc. This trust is more difficult if they do not know the authors and countries of data they receive, such as the seniority of the author and the healthcare context in that country. Professionals have concerns that they may be liable for errors in a source document that they rely on. For an International Patient Summary to deliver direct care benefits, clinicians need to be able to determine the provenance of received information, rely on it appropriately and re-collect only the data necessary to support robust decision-making.

Strategic objectives:

- Promote the development of guidance and training for all health professional disciplines and specialties, and patients, about the creation, maintenance and use of good quality health records that result in good quality patient summaries being produced.

Recommendations:

EU and US policy makers with support from eHealth/health IT stakeholders, in particular educators, health professional and provider associations, patient advocacy groups and developers of eHealth/health IT solutions should:

- promote the development of guidance and training for all healthcare professional disciplines and specialties, and patients, about creating, maintaining and using high quality health records, including the appropriate use of patient summaries in the IPS standard to inform clinical decision-making;
- foster initiatives that motivate and equip patients to maintain and harness their own health summary information in the IPS standard for better health and the self-management of health conditions.

4.1.5 Incentives

This topic area explored the possible financial and non-financial incentives that may encourage the level of quality and completeness of Electronic Health Records that is necessary for the implementation and deployment of efficient and effective Patient Summary that uphold high quality care and patient safety. This is critical since safe clinical decision-making on the basis of a communicated Patient Summary relies upon its accuracy and completeness (e.g. allergy list, medications), whereas clinicians are not currently very motivated to maintain summary data within their own systems (they often know their own patients well).

The ready availability of useful Patient Summaries to support safe and effective care to unfamiliar patients will require health professionals to invest time in maintaining good quality summaries on all of their patients, and for the wide scale deployment of EHR systems that support the transatlantic or global exchange of patient summaries in the International Patient Summary standard. Incentives may be required for different stakeholder groups to achieve this.

Strategic objectives:

- Determine the financial and non-financial incentives needed to encourage high levels of adoption of high quality patient summaries, and for the deployment of conforming EHR systems.

Recommendations:

Healthcare payers and insurers should consider:

- rewards and incentives for health care providers to maintain complete, up-to-date health records that enable the generation and sharing of accurate patient summaries in the IPS standard.

Healthcare professional associations should consider:

- licensing and accreditation schemes that demonstrate competence and commitment to accurate and complete clinical documentation that enables the creation, maintenance, and communication of patient summaries in the IPS standard.

Health providers should consider:

- quality criteria on maintaining accurate health records in the appraisal of healthcare professional staff and other relevant care givers to support effective exchange of patient summaries in the IPS standard.

4.1.6 Privacy and security

This topic considered adoption strategies for addressing legal issues, eIdentification, security and privacy protection and the establishment of a transatlantic trust framework as a step towards developing a global trust framework. A consent and a trust model are needed to ensure information transfers are lawful and meet concerns at each level down to individual healthcare sites. For example, information sharing agreements may be needed, access policies either need to accompany each summary, or be agreed in advance, including about the onward propagation of a received summary. Interoperability of authorisations and purposes of use need to be mapped, and identities and roles of staff at each site need to be cross verified.

The cross-border sharing of patient data, even if for direct patient care, must be demonstrably undertaken in a trustworthy and liable way. Current practice in both sides of the Atlantic does not always meet these requirements as health data is often exchanged through non-secure means such as email and fax. In some cases, this is can be attributed to lack of confidence on the part of the professionals on the level of legal protection against privacy related litigation. Hence, clarity in the application of data protection legislation to the health sector and implementation of organizational and security measures (safeguards) at the providers' organizations are pre-requisites to establishing the needed level of trust on the side of the physicians.

The legitimate approaches for sharing data for health purposes across the Atlantic and the needed safeguards thereof, must be agreed. Such safeguards may also become part of design requirements (privacy by design) of systems facilitating this exchange. Examples of such safeguards are measures taken to ensure that

- it is possible to verify that a Patient Summary is only sent to a recognised healthcare provider who is in charge of that patient at that time;
- the sender is a trusted information source, as well as that the receiver is;
- the identity of the patient is verified, which is especially important if the patient is authorising the communication;
- the patient has a priori authorized emergency overrides and is subsequently informed of such access to health data;
- no sharing of identifiable patient records is possible without patient knowledge, whether this occurs for direct patient care, for reimbursements or for other purposes.

Strategic objectives:

- Legislation must act as an enabler of transatlantic business use cases involving sharing of health data.

Recommendations:

EU and US policy makers should:

- develop and adopt a legal framework enabling the safe and secure global exchange of patient summaries in the IPS standard;
- develop and enact legal agreements to enforce and assure the implementation of organisational and security safeguards needed to underpin global exchange of patient summaries in the IPS standard between providers;
- define policies specifying the safeguards and measures needed to protect citizens in the cross-border exchange of patient summaries in the IPS standard including, but not limited to, identity management, access controls and audit trails.

4.1.7 Research

The International Patient Summary Standard will need, in time, to be complemented by other summaries for specific disease or care scenarios. It will therefore be important to engage the health informatics and clinical research communities in developing threads of research that will take this field forwards. Research is needed on the quality of summaries generated at scale, on the relevance of the included data items and any essential gaps, and on the safety and effectiveness of clinical decisions made using the summary. Research will also be needed to collate evidence of value in a shared patient summary, to inform the development of other kinds of patient summary and to empower patients as users of their health summary.

The success of sharing patient summaries will require many areas of further research. The International Patient Summary will need evaluation, especially benefits realisation and success strategies for scaling up adoption. Future patient summaries may need to be developed with enriched content for specific diseases, and to cater for planned care scenarios. In parallel, research is needed on how patients may best use their own access to the summary as a tool for empowerment and the co-production of health.

Strategic objectives:

- Fund new research to collate evidence of value in the shared health summary, to inform the development of other kinds of health summary and to empower patients as users of their health summary

Recommendations

EU and US policy makers should promote:

- joint research on metrics for assessing the quality of patient summaries in the IPS standard;
- allocation of resources to monitoring the implementation of the IPS standard and its impact on improving patient safety and effective continuity of care, such as more efficient emergency diagnosis, reduced adverse drug events and reduced duplicate investigations.

4.2 Approaches recommended to achieve these objectives

4.2.1 Future standardization

Formalised collaborations between SDOs must result in well aligned, harmonised standards that can be used seamlessly together to deliver relevant interoperability functionality. These collaboration agreements should lead to a singular portfolio of standards per high level function that are supported by all SDOs as a collective solution to interoperability. The JIC has an important role to play in this setting.

Priorities for standards development need to include:

- relevant terminology reference sets and value lists bound to information structures for each of the categories of information to be included in summary, along with a robust governance methodology for evaluating and maintaining these;
- clinical information structures to formalised the data structures for each of the main headings of information to be included in the international patient summary, that are globally agreed and interface cleanly with terminology value lists;
- internationally standardized access policy frameworks to enable global conformance to any access rules specified by the patient or their healthcare professionals;
- identity management including eID, recognised across Europe and related to a standardised representation of user authorisations.

Standards that support the interoperability of health information must address the clinical requirements for the inclusion of provenance data, and for ensuring appropriate access controls for the communicated information.

SDOs and other producers of terminology systems need to make available reliable and quality assured translations of their terminologies across European languages and cross mappings to other relevant terminologies. These syntax and terminology mappings should be targeted at helping to avoid the risk of erroneous duplication of information when summary data are integrated from multiple source systems that have used different terminology systems.

The process for developing healthcare semantic standards needs to consider compositional language approaches and not only specialising and constraining information models.

Profiles of a standard developed separately need to be regularly consolidated for consistency and ease of use.

Clinician and patient interoperability requirements for specific shared care scenarios must be understood before the scope and detail of standards to deliver that interoperability are specified.

The development of the standards need to better align the purposes of direct care with clinical research, public health and other aggregated (“secondary use”) data uses.

Individual standards need to have a well described scope and intended exploitation purpose before they are developed. There needs to be a published method of validating that the resulting standard does fulfil its intended scope, and if there are any important limitations or issues relating to its adoption for that scope.

Interoperability assets need to be promoted internationally, and openly accessible in a range of relevant computable formats (including for example semantic web formats), to encourage their adoption.

Governance and authorisation agreements, between countries, are needed to endorse the adoption of international patient summary rather than using local or national ad hoc standards.

We need to rethink standards development, deployment and maintenance, with most standards being published electronically, in computable formats for ready incorporation into tools and products.

4.2.2 Cross-vendor integration

Vendor support for the export and import of Patient Summaries in IPS needs to be promoted as a societal responsibility in addition to being included within future procurement specifications for EHR systems. This in turn needs to be backed by trustworthy technical and legal infrastructures to enable the cross-border exchange of Patient Summaries in IPS.

Conformance assessment needs to go beyond simulation through reference implementations and test datasets, and be closer to real world validation with a realistic set of user organisations and local system configurations, including some typical legacy environments with a more basic infrastructure and with realistic existing systems and data.

There needs to be a better fit between the expressions used by clinicians in different care settings, and by patients, and the representations supported by standards: structures, vocabularies - especially in safety critical areas such as allergies and adverse drug reactions. Care plans need to be genuinely team based, and incorporate inputs from patients as well as clinicians. The provenance of health information, including its currency, must be represented and included consistently within the shared information. Pre-competitive cross-vendor collaboration is needed to ensure that such clinically-driven specifications are not locked within proprietary implementations.

Requirements for interoperability need to be enforced. Investment and cross-vendor collaboration is needed to lobby for regulations in support of transatlantic health information exchange that will bring patient benefit.

4.2.3 Innovation

Demonstrate the success and value of sharing patient summaries in IPS, globally, potentially using highly visible international events such as a future Olympic games and other scenarios of high societal value.

Efforts and strategies towards a clinically consistent and technically standardised summaries must be global, using and contributing to international standards, to avoid fragmentation within the marketplace of implementations. This should be complemented by promoting a culture of using standards rather than inventing local solutions, while at the same time encouraging invention of new systems and methods of bridging gaps when current standards are inadequate and of seamless transition between old and new standards.

Establish and promote independent, international, non-governmental entities that certify and promote small businesses that function as trusted third parties (TTPs). While the TTP certifying entity may be initiated with government grants, revenues from business incubation and differentiation, business owner-investor meet-ups, certification, marketing, and education will drive the entity's long-term sustainability and profitability. These entities will certify TTPs which, through software, web, and customer-support services, curate and aggregate computable patient summaries, enable patients to find and successfully report inaccuracies in summaries, permit exclusively patient-authorised access to health summaries, and link summaries to patient-specific information derived from multiple sources including EHRs and to patient-relevant knowledge and decision supports. As a minimum, TTPs must repeatedly demonstrate that their management of clinical summaries conforms to international standards, functioning as the most reliable single point of information available about each patient's health history and health status.

Patients must be supported to be well prepared, and motivated, to engage in self-management and the management of their health information, recognising that the patient perspective (and therefore their health information) will reflect not only the science of their conditions but the impact their health

status has on their lives. This may lead to patients becoming accredited in self-management skills through eHealth tools (“ePatients”).

Encourage the development of innovative business models for Patient Summary exchange, including incentives for current stakeholders to invest in compliance to IPS.

4.2.4 Education

Healthcare professional education is needed about the role and ideal content of an international patient summary and its possible extensions, how and how often the relevant information should be updated, how to best use summaries to facilitate well-integrated person centred care and how to share their maintenance and use with patients.

Healthcare professionals also need to understand the extent of trust and reliance they can/should place on a patient summary in the IPS standard received from elsewhere, and the reliance to place on content that has been mapped from other terminology systems or translated between languages.

Healthcare professionals and patients both need to understand some of the key principles of health informatics and interoperability, in particular about the use of clinical terminologies and clinical information structures to construct and populate patient summaries, and about the value and limitations of mappings to broker across heterogeneous terminologies and languages.

Healthcare professionals and patients should understand about the role of information security to protect privacy when summaries are shared, the limitations of what can be achieved through security measures, and the roles that they can play in ensuring that good information governance practice is followed.

Patients, and healthy citizens should have opportunity to learn about how to maintain their patient summary in the IPS standard, and/or to collaborate with health professionals on a shared summary, and how to use this, potentially along with more detailed health information, to become more active in their own health and wellness strategy, healthcare decision-making and empowerment.

A starting point would be implementing initially a joint US/EU Educational program with global scope, in collaboration with professional associations and patient advocacy groups, to advance the above topics.

4.2.5 Incentives

Healthcare professionals will feel incentivized to configure and maintain patient summaries in IPS if their design is professionally led, reflects the information that they believe most relevant to their specialty perspective on the patient, and not through automated summary generation that results in overcrowded extracts of the less relevant information. The incentive will be greater if we can reach consensus across specialties on a single summary (or extending summary profiles for specialties or diseases) that can genuinely allow interdisciplinary collaboration.

From the patient perspective, the value of the patient summary in IPS would be best if it can be understood by them and accepted by health professionals around the world.

Health care providers should be reimbursed or given other incentive payments for maintaining complete and up-to-date summaries on their patient populations. In redesigning processes attention should be paid to the impact on workload and workflow from the effort required to maintain high quality summaries in the IPS standard.

It should be a required component of healthcare professional accreditation and staff appraisals that they can demonstrate competence and commitment to creating and updating patient summaries on their patients in the IPS standard.

Patients should be given incentives through their health insurer, such as discounted premiums, if they maintain an up-to-date health and wellness summary, or demonstrate that they contribute to a summary maintained by their local health care provider. Patients should be incentivised to receive

training and become accredited “ePatients”. At the same time, they should be aware of their rights to their patient summary for emergency or unplanned care and know how, in case of need, to grant access to it.

An important incentive will exist when it is possible to demonstrate how good quality shared patient summaries in IPS make continuity of care safer, more efficient and cost effective. Metrics are needed on how to assess the quality of a patient summary, and on how to demonstrate the value of sharing good-quality patient summaries in the IPS standard.

The incentives we develop need to recognise effort made by healthcare professionals to create and curate clear, concise and up to date patient summaries in the IPS standard and more also generalised efforts made to ensure high quality documentation within electronic health records, which provide the source data to inform summaries.

Local incentives can produce local results that enable initially cross-border and gradually global exchange of patient summaries in the IPS standard.

4.2.6 Privacy and security

Legislation: Health Data exchange must have a clear legal basis. There is general legislature regulating the free flow of data within EU, within the USA and across EU and USA, namely the Safe Harbour framework. epSOS has addressed the implications of the Data Protection Directive for sharing health data across borders in the EU. It is necessary to extend the epSOS analysis to transatlantic exchanges, taking onto account the cultural and organizational diversities, as well as the evolving legislation on both sides of the Atlantic. This should be only a step in taking this analysis to the global level.

Agreements: Although the common EU data protection framework and its transatlantic alignment through the Safe Harbour Agreements provide the general legal framework, there will need be an agreement on specific organizational and security safeguards. The epSOS FWA and DURSA in the US are examples of such agreements between several MS or inter-state organizations in case of the US to run a cross border pilot; the need of similar agreements establishing the circle of trust is anticipated also for any transatlantic pilot services as a step towards similar services at the global level. Legal means to secure the sustainability of these agreements beyond the lifetime of pilots, will need to be explored early on.

Codes of practice: agreed and enforceable codes of practice, and practical safeguards, on privacy and data protection support the implementation of the agreements and improve auditability for proactive monitoring and periodic audits undertaken by nominated credible authorities or entities on both sides of the Atlantic.

4.2.7 Research

Research is needed on the following subjects to inform best practices and adoption strategies for the international patient summary and its possible future extensions:

- Interdisciplinary, shared representations of patient summary information, of care provided and treatment recommendations, to support continuity of care and patient safety.
- The most effective ways to represent the context and situatedness of clinical judgements, and to account for clinical uncertainty.
- Ways to reduce the effort of defining and representing health information.
- Research into ways of identifying high-risk individuals from their EHR data (e.g. frailty).
- Care pathways and decision support rules that cater better for multi-morbidity.

- Best practices for putting patients more strongly in control of healthcare decisions and health information flows regarding their data.
- Best practices in motivating and educating patients to curate the information needed for their own health summary, including different modalities of content and different channels such as social media.
- Best practice in educating patients to better communicate their health situations to health care providers, for example the use of patient stories depicting different health, emotional and stress scenarios, and educating patients in how to pose the right questions to their health care providers about treatment options including their costs.
- Identifying patients subgroups for whom the curation of their own health information and communication with healthcare professionals is difficult, which could be for health status, socio-economic, age income, literacy, or cultural reasons, and better equipping them to advocate for their health needs.
- Metrics on how to assess the quality of a patient summary in IPS, and on how to demonstrate the value of sharing good-quality summaries in the same standard.

Appendix 2: Trillium Bridge Preliminary Action Plan for the EU

This appendix reflects some preliminary suggestions for actions that could be taken in the short term (12-18 months), medium term (18-36 months), long-term (36-54 months) from a European Perspective, referencing the Trillium Bridge recommendations.

Short Term (2015-2016)

- Update the European Patient Summary guidelines to align with the IPS [R#1-R#5]
- Identify and publish Trillium Bridge assets as part of EXPAND asset repository [R#1-R#5]
- Organize EU/US IPS workshops for patient advocacy groups, SDOs, and physician and health informatics associations [R#2]
- Deliver draft versions of information structures and associated value sets for IPS components [R#1-R#5]
- Assess the use of SNOMED CT to express clinical problems and procedures in the IPS [R#1-R#5]
- Extend the European eHealth Interoperability Framework with further use cases making use of the IPS [R#1-R#5]
- Share Trillium Bridge findings with the clinical research and pharma community [R#3]
- Share Trillium Bridge findings with patient safety and clinical quality communities
- Seek endorsement for the social value of the IPS effort with global organizations e.g. WHO, United Nations [R#2]
- Investigate possible IPS extensions for public health, registries, secondary use, rare & chronic diseases [R#3]
- Develop a governance process for IPS updates with the JIC for global SDO health informatics standardization [R#2]
- Create high visibility demonstrators of IPS use cases with IPS import/export from EHR systems [R#6, R#7]
- Facilitate use of the European Medicines Database by consumers in the frame of the IPS [R#1-R#5, R#7]
- Deliver IPS training material for eHealth/Health IT stakeholders, especially caregivers and patients [R#17-R#18]
- Align epSOS/EXPAND/CEF and US (eHealth exchange) of IHE XCPD/XCA profiles for Patient Id and Query/Retrieve [R#1-R#5]

Medium Term (2017-2018)

- Deliver a legal framework for safe and secure global IPS exchange for emergency or unplanned care [R#14]
- Launch pilots in innovative global communities to validate security and privacy policies for IPS exchange [R#8, R#14-R#16]

- Identify and support global communities of innovation implementing the IPS using mHealth [R#9]
- Develop a roadmap for the deployment, incremental refinement and broad adoption of IPS [R#1-R#5]
- Create and validate incentives for maintaining health records that can support high quality IPS [R#11-R#13]
- Assess through validation pilots the use of IDMP for the identification of medication in the IPS [R#1-R#5]
- Set up pilot demonstration projects using global communities of innovation to confirm validity and utility of the IPS [R#9]
- Develop testing tools and quality assurance processes for the conformance testing of IPS [R#6]
- Develop and effect governance structures for the update of the IPS with update of the EU guideline on PS [R#2]
- Support innovative procurement approaches for the deployment of IPS [R#9-R#10]
- Establish critical mass in global IPS adoption with engagement of a broad range of stakeholders [R#9-R#10]
- Clarify licensing of information structures and associated terminology sets [R#9-R#10]
- Promote the use of the IPS encourage, aid and abet, and monitor the early adopters of the IPS [R#9-R#10]
- Develop, test and validate business models for the support of high quality IPS [R#9-R#10]
- Support pilot implementations of IPS in global communities of eHealth innovation [R#9-R#10]
- Develop, test and validate an extension of the IPS fit for use in Healthcare Encounter Reporting
- Develop indicators to monitor and share experience on the use and impact of IPS [R#20]
- Develop indicators to monitor the quality of the IPS [R#2]
- Set up and evaluate comprehensive modes for personal health information stewardship using the IPS [R#10-R#11]
- Include the semantic content required of the IPS in a free accessible repository
- Have the semantic content of the IPS (in particular data structures, vocabulary) be validated by clinical and patient organizations.

Long term (2020)

- Adopt the IPS for specific purposes such as public health
- Validate possible extensions of the IPS for secondary use
- Monitor and share experience on the use, quality and impact of IPS use [R#19-R#20]
- Refine clinical information structures and associated terminology value sets for the IPS using the adopted governance structure. [R#1-R#5]
- Incorporate the IPS in public procurement [R#10]
- Study the benefits of the IPS specifications for public health through pilots

- Study the benefits of the IPS specifications for adverse drug reporting
- Study the benefits of the IPS specifications for disease management
- Develop, test and maintain measures of global IPS adoption

Next Steps

Moving forward these recommendations that are structured around key activities, we need to structure them along different dimensions that highlight interdependencies in terms of content, preconditions, scope, method, and timeline, as well as relevant projects, organizations and level (MS, EC).

A larger group could facilitate the potential next steps and the validation/endorsement process. The first step in that direction would be a refined action plan with interdependent elements some of which can proceed in parallel while others must be part of sequential processes. The second step is to identify actors, structures, initiatives, and projects looking into the gaps and working to bridge them. The next (third) step would be to align with the eHN priorities and workplan, assuming some form of reciprocity from the US, perhaps in the context of the roadmap, possible addressing both the federal and the state level.

Appendix 3: Transatlantic Community of Trillium Bridge: advisors, experts, supporters, contributors

This is a list of people from around the world that have contributed, supported, and advised Trillium Bridge in its efforts to bring closer the two sides of the Atlantic. This is intentionally a list of persons, we are also grateful to various associations that have supported us along the way, such as the OpenNCP community, EFMI, the JIC, EN13606 Association, HIMSS, CEN TC251, IHE, and HL7. Despite my effort to be inclusive and take this opportunity to express my gratitude to every single one of them, I am sure there are omission to which, I have to apologize in advance!

Catherine Chronaki, July 6, 2015

Name	Last	Country
Iciar	Abad Acebedo	Spain
Benoit	Abeloos	Belgium
Anna	Adelof	Sweden
Mindaugas	Ajauskas	Italy
Liora	Alschuler	United States
Najeeb	Al-Shorbaji	Canada
Rui	Alves	Portugal
Clemens-Martin	Auer	Austria
Landen	Bain	United States
Herve	Barge	Luxemburg
Alexander	Berler	Greece
Sören	Bittins	Germany
Rachelle	Blake	United States
Elaine	Blechman	Uited States
Mina	Boubaki	Greece
Abderrazek	Boufahja	France
Karima	Bourquard	France
William	Braithwaite	United States
Giorgio	Cangioli	Italy
Nicolas	Canu	France
Alexandra	Carbal	Portugal
Jim	Case	United States
Mera	Choi	United States
Catherine	Chronaki	Greece
Christopher	Chute	United States
Marie	Cleary	Ireland
Ronald	Cornet	Netherlands
John	Crowford	United Kingdom
Isabella	Cruz	Portugal
Gerald	Cultot	EC
Frank	Cunnigham	EC
Samuel	Danhardt	Luxemburg
Beatriz	de Faria Leão	Brazil

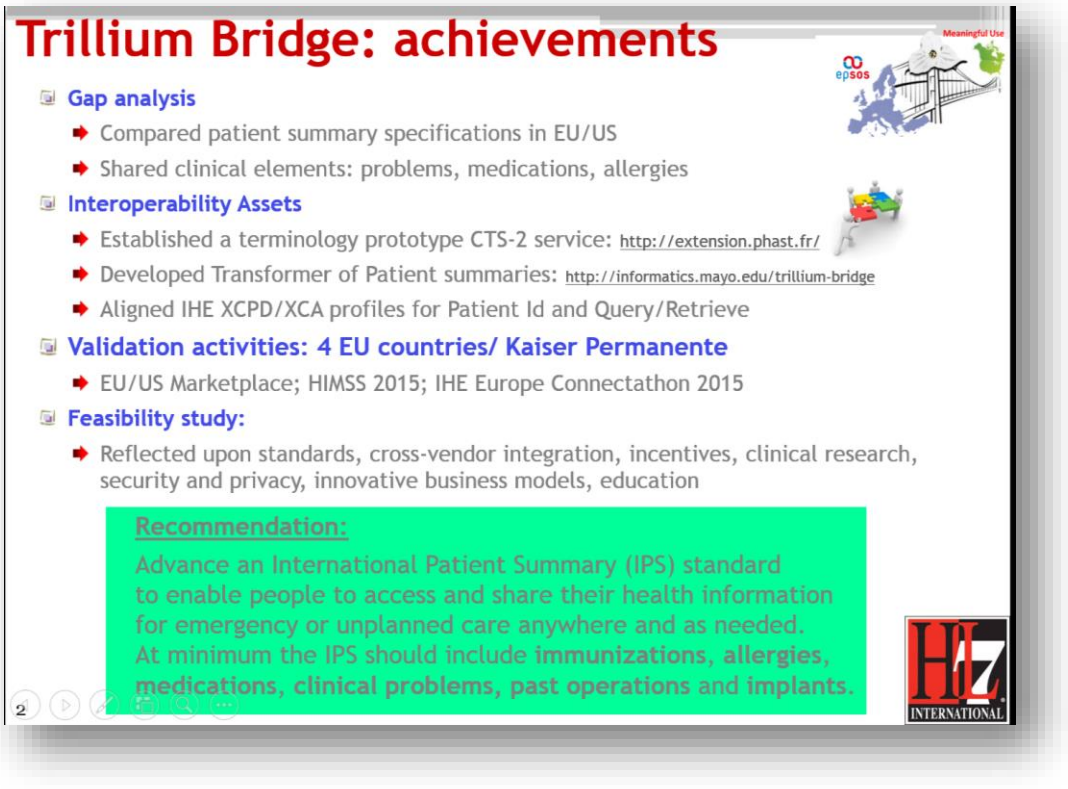
Simon	de Lusignan	United Kingdom
Georges	De Moor	Belgium
Ana	Delgado Roy	Spain
Nicole	Denjoy	France
Gary	Dickinson	Belgium
Richard	Dixon-Hughes	Australia
Robert	Dolin	United Sates
Ana	Esterlich	France
Jamie	Ferguson	United States
Mircea	Focsa	Romania
Marcelo	Fonseca	Portugal
Gerard	Freriks	Netherlands
Doug	Fridsma	United States
Charles	Friedman	United States
Lawrence	Garber	United States
Sarah	Gaunt	Australia
Franck	Gener	France
Christof	Gessner	Germany
Suzana	Getman	United States
Zachary	Gillen	United States
Shirin	Golyardi	The Netherlands
William	Goosen	The Netherlands
Tomaz	Gornik	Slovenia
Angela	Granum	United States
John	Halamka	United States
Leslie Kelly	Hall	United States
Ed	Hammond	United States
Kyriakos	Hatzaras	United Kingdom
Christian	Hay	Switzerland
Eric	Heflin	United States
Matthew	Hein	United States
Stan	Huff	United States
Russ	Humm	United States
Paolo	Invernizzi	Italy
Kevin	Isbel	United States
Charles	Jaffe	United States
Gayathri	Jayawardena	United States
Virginia	John	United States
Kostas	Kaggelidis	Greece
Dipak	Kalra	United Kingdom
Kostas	Karkaleksis	Greece
Stephen	Kay	United Kingdom
Zoi	Kolitsi	Greece
Maritta	Korhonen	Finland
Ulrike	Kreysa	Brussels
Joy	Kuhl	United States

Rebecca	Kush	United States
Licinio	Kustra Mano	Portugal
Vishaun	Lekraj	United States
Fredrik	Linden	Sweden
Alexander	Lippit	United States
Marian	López Orive	Spain
Christian	Lovis	Switzerland
Gonzalo	Marco Cuenca	Spain
Lilia	Marques	Portugal
Juan Pablo	Martínez Bartuilli	Spain
Henrique	Martins	Portugal
Massimiliano	Masi	Austria
Rosy	Matheson	United Kingdom
Matic	Meglic	Slovenia
Marcello	Melgara	Italy
Alexander	Mense	Austria
Amanda	Merril	United States
Pier Luigi	Miglioli	Italy
Garrett	Miles	United States
Jane	Millar	United Kingdom
Anna	Moen	Norway
Arlete	Monteiro	Portugal
Alberto	Moreno Conde	Spain
Enrique	Mota López	Spain
Juan Fernando	Muñoz Montalvo	Spain
Juha	Mykkanen	Finland
Don	Neusbaum	United states
Luc	Nicholas	Belgium
Michael H.	Nusbaum	Canada
Brian	O'Connor	Ireland
Damien	O'Connor	Ireland
Andrej	Orel	Slovenia
Luca	Pagliara	Italy
Charles	Parisot	France
Jamie	Parker	United States
Carlos Luis	Parra Calderón	Spain
Terje	Peetzo	EC
Jan	Petersen	Denmark
Kevin	Peterson	United States
Ivo	Pinheiro	Portugal
Rui	Pinto	Portugal
Antti	Pohjolainen	Finland
Eric	Poiseau	France
Luis	Porter	United States
Fernando	Portilla	Uruguay
Jorge	Rangil López	Spain

Virginia	Rhiel	United States
Andrea	Ribick	United States
Wes	Rishel	United States
Mark	Roche	United States
Michael	Rogers	United States
Arturo	Romero Gutiérrez	Spain
Stefan	Sabutsch	Austria
Charles	Safran	United States
Liuska	Sanna	Belgium
Alexandre	Santos	Portugal
Rene	Schippers	Netherlands
Falk	Schubert	Germany
Stephan	Schug	United States
Philip	Scott	United Kingdom
Amnon	Shvo	Israel
Daise	Smet	Luxemburg
Harold	Solbrig	United States
Stéphane	Spahni	Switzerland
Lisa	Spellman	United States
Michiel	Sprenger	The Netherlands
Craig	Stancl	United States
Robert	Stegwee	Netherlands
Lacri	Stoicu-Tivadar	Romania
Veli	Stroetmann	Germany
Lawrance	Stulz	United States
Don	Sweete	Canada
David	Tao	Canada
Michele	Thonnet	France
Jeremy	Thorp	United Kingdom
Sylvia	Thun	Germany
Paul	Timmers	EC
Kim	Tuminaro	United States
Rossana	Ugenti	Italy
Robert	Vander Stichele	Belgium
Celia	Varela Núñez	Spain
Patrick	Weber	Switzerland
Petra	Wilson	United Kingdom
Ann	Wrightson	United Kingdom
Dillan	Yogendra	United Kingdom
Zabrina	Zarubina	United States
Heiko	Zimmermann	Luxemburg
Roberto	Zuffada	Italy

Appendix 4: Endorsements to the key Trillium Bridge Recommendation

Following the compilation of the Trillium Bridge recommendations and draft action plan, we shared them with leading experts and thought leaders in the transatlantic community of Trillium Bridge and requested an endorsement.



Here is what they shared with us.

(1)

"With the Trillium Bridge analyses, proposed strategies and feasibility studies we now know what should be done and how to do it. So let's do it! "

Niels Rossing,
Former head of EU R&D Programme for Health Telematics
Denmark, June 24, 2015

(2)

"Developing the IPS and associated rigorous testing can be a first important step towards advancing the patient benefits of IT beyond the boundaries of individual care delivery organizations and countries."

Wes Rishel
Former Vice President
Distinguished Analyst at Gartner
United States, June 23, 2015

(3)

I am hugely impressed with work completed by the Trillium Bridge team, much more than I expected. Their recommendations have emerged from intense activity and reflect the wide-ranging expertise of the Trillium team. In particular, the key recommendation to advance an International Patient Summary is welcomed not only in principle, but also because the Trillium Bridge team has clearly demonstrated the feasibility of effecting such patient summary data exchange between countries in Europe and across the Atlantic.

Jeremy Thorp
Director of Business Architecture
Architecture, Standards and Innovation
Health and Social Care Information Centre United Kingdom, June 23, 2015

(4)

"The work of Trillium Bridge is key to the creation of the real tools which will enable the implementation of the IPS. The leadership shown by Trillium should be applauded and the patience and determination necessary to persuade many stakeholders across continents should not be underestimated."

Brian O'Connor
Chair, European Connected Health Alliance
United Kingdom, June 25, 2015

(5)

"Trillium Bridge has brought us further along the shared aspiration of cross-border health information interoperability than any previous effort. Their core recommendation remains the singularly most important goal within for the traveling public who require healthcare abroad."

Christopher G Chute, MD DrPH
Chair, ICD11 Revision Steering Group, WHO
Former Chair, ISO TC215 on Health Informatics
Bloomberg Distinguished Professor of Health Informatics
Professor of Medicine, Public Health, and Nursing
Chief Health Research Information Officer, Johns HopkinsMedicine
United States, June 20, 2015

(6)

"I think this is a good and timely recommendation given the increase in international travel, and especially travel related to "medical vacations."

Stan Huff, MD, PhD
Chief Medical Officer, Intermountain Healthcare
HL7 International Chairman of the Board
United States, June 24,2015

(7)

"People traveling between Europe and the United States alone account for over a half million emergency department visits each year. The Trillium Bridge project showed that not only is it possible to transform medical summaries between the languages of various countries, but also that it is crucial to create an International Patient Summary standard for the wellbeing of millions of citizens of the world."

Larry Garber, M.D.
Medical Director for Informatics
Reliant Medical Group
United States, June 23, 2015

(8)

Trillium moved forward the boundaries drawn before by epSOS : seamless exchange of patient summaries is not only possible in the European realm but goes beyond, through the Atlantic Ocean to USA : patient summaries edited in Europe are readable in USA and vice-versa. Trillium achieves the proof of concept and opens a new challenge : to meet the conditions to turn this experiment into a daily basis process, with the relevant infrastructure alongside the economic model.

Franck GENER
Pharmacien, Praticien hospitalier
Chargé de missions
Association « Réseau Phast »
Paris, June 24,2015

(9)

"By defining IPS, Trillium Bridge has produced one of the pivotal points in eHealth standardisation, opening new opportunities for eHealth industry to deliver value to patients, providers and health systems on both sides of the Atlantic."

Matic Meglic MD PhD MBA
Strategy and Business Model Innovation Director
Medtronic International
Switzerland, June 26, 2015

(10)

"International Patient Summary (IPS) standard, setting expectations for content and strategies to enable access to critical health information at the location and time of need is timely and important for our colleagues in EFMI. A helpful IPS could include current medication, treatment for current health problems, allergies, intolerance and resistance, immunizations and emergency contact information, preferably at the discretion and consent of the citizen."

Professor, Dr. Anne Moen, president, European Federation for Medical Informatics (EFMI)
Norway, June 26, 2015

(11)

"The value of patient summary records to improve the safety of unplanned medical care is now widely accepted. The epSOS project, which IBM supported, demonstrated how such records might be accessed across national borders within Europe. We welcome the Trillium Bridge recommendations to extend the reach of patient summaries further, based on international collaboration and consensus, and we fully support such an approach."

J (John) Crawford
Healthcare Industry Leader, Europe
IBM Industry Academy Member
United Kingdom, June 26, 2015

(12)

"Patient safety and the delivery of good quality care are top priorities for healthcare providers. Access to patients' health information in case of emergency or unplanned care can be crucial to provide the right diagnosis and treatment. HOPE therefore supports the final recommendations of Trillium Bridge project to advance on an international patient summary standard which will enable to enhance interoperability and share of information for a better continuity of care"

Pascal Garel
Chief Executive,
HOPE - European Hospital and Healthcare Federation
Belgium, June 26, 2015

(13)

"I had the privilege, when I was in government service at the ONC, to collaborate with terrific colleagues on both sides of the Atlantic in the development of the EU-US Memorandum of Understanding on Health IT. From the moment we conceived the "MOU", we had in mind that the resulting trans-Atlantic cooperation would lead to the reality of a health summary record that could be seamlessly exchanged across the waters. Trillium Bridge has moved us closer to that vision. It is the right vision, in my opinion, and one toward which we must continue to progress."

Charles P. Friedman, PhD
Department Chair of Learning Health Sciences
Josiah Macy Jr. Professor of Medical Education
Professor of Information, Professor of Public Health
United States, June 26, 2015

(14)

Having Trillium Bridge recommendations in mind, EU Member States as well as the USA are in a position to consider recommending or requesting International Patient Summary (IPS) implementation for every citizen (near to 100% coverage).

Arturo Romero Gutiérrez
Ministry of Health, Social Services and Equality, Spain
Arturo Romero Gutiérrez
Director del Proyecto HCDSNS
Subdirección General de Información Sanitaria e Innovación
Ministerio de Sanidad, Servicios Sociales e Igualdad
Spain, June 25, 2015

(15)

"The recommendation to develop and adopt of an International Patient Summary (IPS) standard is the right way forward to improving patient safety and collaboration across the Atlantic. With travel and medical tourism reaching a new level every day, it has become essential to have a standard that will allow for secure, interoperable and seamless data exchange between countries, professionals and systems. Success of this between USA and EU will pave the way for a global undertaking. Global health knows no boundaries and standardization should facilitate better management of health data for better healthcare to individuals and at global level."

Najeeb Al-Shorbaji,
Director, Knowledge, Ethics and Research Department
World Health Organization
Switzerland, June 29, 2015

(16)

For many of the healthcare IT professionals dedicated to the development and adoption of international standards, the work of Trillium Bridge has been instrumental in defining a key enabler of worldwide interoperability of health information. I fully support the recommendation for an International Patient Summary standard that will facilitate the availability of health information anywhere on the globe, as this represents the ultimate goal for healthcare leaders and standards bodies alike to ensure high-quality care. The next step is to leverage the great work of Trillium Bridge by publically demonstrating the value of clinical interoperability across national borders, through initiatives such as the Olympic Games.

Michael H. Nusbaum, BASc, MHSA, FHIMSS
IHE International Board
United States, June 29, 2015

(17)

"Congratulations to the team developing these DRAFT recommendations. It comes as a milestone achievement for the Trillium Bridge project, a major step forward and clearly, a triumph for safe and trusted exchange of patient summaries among regionally and internationally connected providers. Especially appreciate attention given to ensure authenticity of health record/data content exchanged, with clear traceability to source and provenance."

Gary Dickinson
Director, Healthcare Standards, CentriHealth
Co-Chair, HL7 EHR WG
United States, June 27, 2015

(18)

"..for us it will be very important the recommendations that IPS project have done, now our countries are in early stages; the agreements, the experience and the knowledges it will so usefully to avoid mistakes and to work in focus areas. Even to consider any topics that we don´t have in the scope now and it could be necessary to include in our framework, for example: the cross-vendor integration. "

Fernando Portilla,
Rep. of Uruguay in the RACSEL network
Uruguay, June 25, 2015

(19)

"Europe and US have successfully set - via the transatlantic Trillium Bridge project - a new International Patient Summary (IPS) standard that will have a real impact on the solutions provided by EHR-system vendors globally."

Georges De Moor,
Professor and head of the Department of Health Informatics and Medical Statistics of the University of Ghent
Ghent, July 3, 2015

(20)

""Trillium bridge demonstrated that the consistent use of IHE Profiles to identify patient (XPDQ) and query/retrieve(XCA) patient summaries both across Europe as defined by epSOS and across the USA as defined by eHealth Exchange, provided a valuable basis of consistency that should be further improved and maintained."

Nicole Denjoy
COCIR
Belgium, July 6, 2015

(21)

"*Trillium Bridge achieved in practice to demonstrate the feasibility of exchanging structured data across the Atlantic. This is a major breakthrough that proves the sustainability of standards towards securing and enhancing cross border care. The future of new innovative ehealth and mhealth services are now one step closer to reality. Stakeholders need now to emphasize on real needs and real uses cases that will enhance quality of care. Innovators and smart SMEs need to be supported to expand this path and create new markets and services. There is not a minute to waste, patient and healthcare providers are waiting.*"

Alex Berler,
Director Consulting Services, Gnomon Informatics
Greece, July 6, 2015

(22)

"Trillium Bridge has fulfilled its bold mission and demonstrated proof of concept for a trans-Atlantic infrastructure enabling patient-mediated and provider-mediated health information exchange. Kudos to Catherine Chronaki for her visionary leadership."

Elaine A. Blechman, Ph.D.
President, Prosocial Applications, Inc.
Professor Emerita, U. Colorado-Boulder
United States, July 5, 2015

(23)
"Trillium Bridge accomplishes far more than enabling the exchange of healthcare data across the Atlantic. It is a tribute to cross-border collaboration and a critical step in establishing a model for interoperability. The Trillium Bridge project is the future of connected health and open medicine."

Prof. Charles Jaffe, MD, PhD
Chief Executive Officer, HL7 International
United States, July 7, 2015

Institutional Endorsements

Joint Initiative Council (JIC) on SDO Global Health Informatics Standardization

The JIC is in the process of endorsing the following recommendation.

The Joint Initiative Council unanimously endorses this key recommendation and, through strategic global leadership in health informatics standardization, we are committed to: enabling practical standards-based health information sharing, contributing to better patient health and more effective health outcomes, and undertaking specific initiatives that address these global needs.
In particular, we are currently focused on bringing together core sets of compatible standards needed to support: use of patient care summaries within and across communities and implementation of the Trillium Bridge recommendation and we are committed to work with others who share these goals.

CEN TC251

*EN/TC 251 welcomes the key recommendation of Trillium Bridge to '**Advance** an International Patient Summary (IPS) standard to enable **people to access and share** their emergency or unplanned care health information anywhere and as needed.'*
CEN/TC 251 recognizes the crucial role of the IPS standard work to help achieve the objectives of cross-border care as formulated by the European Commission. Our aim is to achieve productive collaboration in the activities toward delivery of such a standard, based in part on underlying Global and European Health Informatics standards and specifications. Consequently, we foresee an active role for CEN/TC 251 and its members in the review and adoption of the IPS across Europe.
We have already provided some detailed comments on the elaboration of the recommendations, in order to make them as feasible and sustainable as possible in the short term.

Robert Stegwee, Chair

Health Informatics TC251

Brussels, June 29, 2015

GS1

"GS1 is welcoming Trillium Bridge's findings, in particular since they recognise the need to include traceability information for medication and implants in the IPS. This information contributes to patient's safety and integrates the current and future regulatory requirements set for this kind of products".

Ulrike Kreysa

Vice-President Healthcare, GS1

Switzerland, June 23, 2015

Agence eSanté, National Program of Luxemburg

Trillium Bridge has implemented, starting from a gap analysis of the currently used specifications in EU and US, required interoperability assets and was able to create a running prototype for the cross-border exchange of medical information between the EU and US, which was successfully validated during the IHE-Europe Connectathon held in April 2015 in Luxembourg. Based on the outcomes of Trillium Bridge, further work needs to be done on all interoperability levels. The key recommendation, to proceed and advance with the work on an International Patient Summary (IPS) standard, is of strong interest for us at the Agence eSanté. Particularly in the context of our healthcare system - where patients from neighbouring countries as well as from abroad are treated (for planned or unplanned care) - it will contribute to a better treatment of the patient. Furthermore, such an International Patient Summary can be supported using our national eHealth platform which is able to provide the required services.

Office of the National Coordinator for Health Information Technology, United States

The US agreed in principle on the first 4 recommendations from Trillium Bridge. These elements are likely to be part of the next roadmap.

These 4 recommendations are:
Standards and profile development organizations and eHealth/health IT stakeholders should by 2020:

1. collaborate on developing and adopting an IPS standard to enable the interoperable representation and communication of information about a patient's immunizations, allergies, medications, clinical problems, past operations and implants, building on reusable interoperability assets and tools;
2. work closely with clinician and patient associations in the EU, US, and globally to define, refine, and validate the IPS standard, and establish with them a standing governance process under the Joint Initiative Council of SDO Global Health Informatics Standardization to maintain it in the light of updated requirements, legislation and learning from use of the IPS;
3. target the IPS standard as the means for sharing a core set of clinical data for the purpose of emergency or unplanned patient care, aligning it with other relevant existing standards, and incorporating where possible the needs of public health and other secondary uses of aggregated health summary data;
4. work with producers of multi-national terminology systems to publish reliable and quality assured translations of patient summary value sets between relevant languages and of cross-mappings between terminology systems;

Other organizations

At the time of this writing IHE International and IHTSDO and CDISC are considering endorsement of the key recommendation by their boards.