Towards European Patient Summaries based on Triple Space Computing

Dario Cerizza[1], Emanuele Della Valle[1], doug foxvog[2], Reto Krummenacher[3], Martin Murth[4]

[1] CEFRIEL – Politecnico di Milano, Milan (Italy)
{cerizza,dellava}@cefriel.it

[2] Digital Enterprise Research Institute, National University of Ireland, Galway (Ireland)
doug.foxvog@deri.org

[3] Digital Enterprise Research Institute DERI, University of Innsbruck (Austria)
reto.krummenacher@deri.org

[4] Space Based Computing Group, Institute of Computer Languages, Vienna University of Technology (Austria), mm@complang.tuwien.ac.at

Abstract: Medical practice today still entails sorting through scattered information on a specific patient. Making things more difficult, the EU, in bringing its member states closer together, is encouraging people's mobility, and raises thus the desire for treatment wherever and whenever necessary. Aware of such a problem, the EU has been fostering the adoption of interoperable electronic health records since the early '90s, but an optimal solution has not yet been found. The current trend is in building up a European Patient Summary as a virtual common infrastructure for accessing citizens' critical health data with respect to interoperability, multi-lingualism and security-privacy issues. However, such a demanding objective seems difficult to achieve with available technologies. For this reason we aim at evaluating the development of a patient summary based on Triple Space Computing, an innovative paradigm that is significantly moving towards a new era of the Internet, in which communication is achieved via Semantic Web Services based on persistent publication of information instead of messaging.

1   Introduction

The healthcare organizational structure in all countries is naturally distributed, having a geographical spread of centres at different levels of complexity: from general hospitals down to individual physicians. Thanks to specific community laws [EH05], European citizens have rights to move in any member state having recognized the healthcare services acquired in other member states. Currently, when citizens move abroad, they are often required to re-tell their medical history. So, healthcare practitioners need to record it again and, if necessary, to repeat tests and investigations to complete the picture. As result of this situation, patients' health data is often fragmented and stored differently in different organisations across health services. It should be noted that the medical and economic impact of not knowing a patient's complete medical history is profound. Medical practice today still entails sorting through a stack of lab reports, trying to find information on a specific patient. But tens of thousands people die each year due to medical errors resulting from a lack of immediate access to patient healthcare information [HRI05, CSI05].

In order to increase the efficiency of patient care, healthcare professionals must be able to exchange patient information securely and in confidence and health service administrators must be able to check entitlement to care with ease, security and speed. The ultimate goal is to build a network of complementary centres (hospitals, laboratories, ambulatories, coordination centres, etc.) over EU territory to achieve a logically integrated electronic health record system that can boost the confidence of patients and service users that each and every caregiver is fully informed.

1.1   European Commission Strategies

The provision to healthcare organizations of a complete array of patient information with authorized access is an open challenge of the European Commission (see strategic objective 2.4.11 of June 2005 Work Programme of IST). Computer technologies can offer new possibilities to improve almost every aspect of healthcare, from making medical systems more powerful to providing better health information to everyone. For this reason, Information Society Directorate-General[1] and Health & Consumer Protection DG[2] are sponsoring a series of initiatives and events on eHealth[3].

There are many examples of successful eHealth developments including health information networks, electronic health records, telemedicine services, wearable and portable monitoring systems, and health portals. Since the eHealth solutions promise to improve and enhance the quality and effectiveness of the healthcare services offered to citizens by health organizations, particular attention should be paid in order to avoid the overestimation of the concrete capacities of the developed applications and adopted technologies. The EC strongly suggests [Iv06] to evaluate the promises of such eHealth scenarios so that a number of failures could be avoided saving money and lives.

In order to accelerate awareness and uptake of beneficial eHealth systems and services, in 2004 the European Commission issued an action plan [CEC04] that aims at modernizing European healthcare systems. That plan provides a mid-term roadmap for the development of interoperable healthcare systems in and across member states. To reach this goal, it promotes projects and initiatives within several important policy areas that range from research and rollout of broadband networks in telecommunications to activities in public health. This program outlines the actions that should allow the European Union to achieve the full potential of eHealth systems and services within the European eHealth Area.

Further challenges addressed by the European Commission include the support of actions for covering the development of standards addressing the interoperability of diverse systems and services. Particular efforts are dedicated to the interoperability among electronic health records to enable online services such as teleconsultation,

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[1] DG INFSO: http://ec.europa.eu/comm/dgs/information_society/index_en.htm
[2] DG SANCO: http://europa.eu.int/comm/dgs/health_consumer/index_en.htm
[3] eHealth 2005, Tromsø, Norway, 23-24 May: http://www.ehealth2005.no
    eHealth 2006, Malaga, Spain, 10-12 May: http://www.ehealthconference2006.org

ePrescription and eReferral[4]. In these contexts, the need for future standards is clearly emphasised so as to solve interoperability concerns in a way which will benefit all stakeholders through the possible adoption of open source reference implementations for care services. Currently, there are several efforts that aim at supporting the interoperability initiatives for a European eHealth Area such as RIDE[5], I2-Health[6], SemanticHEALTH[7] and COCOON[8]. In particular the current trend is in adopting a Semantic Web Service based solution [DCB05, DCC06].

Member states' representatives involved in eHealth working groups emphasise that *interoperability is not just a technical matter* [EU04]. It is about legal, ethical, economic, social, organisational, and cultural matters. To approach eHealth interoperability, all these aspects need to be addressed. The result of this process will be a recommendation on European eHealth interoperability which will be issued in 2007. A coordinated effort by all stakeholders – citizens, health professionals, and relevant organisations – accompanied by a wide consultation of interested parties, is necessary in order to agree on such a recommendation.

Although the European Union brings its member states closer together by integrating policies and markets, some socio-cultural and legal differences will always remain. The increased ease of migration results in more mobility of the people and, hence, in a more heterogeneous population, where potential patients come from various countries with other native languages and different medical systems and regulations. The unification of the European medical systems results in the need of inter-country communication and coordination of patient data to ensure the same medical service independent of the current country of residence or place of treatment. In consequence, a doctor or medical assistant needs to be able to access a patient health record at any time and from any place necessary. In fact, it is necessary to ensure ubiquitous access to medical information. In the extreme case people do not have personal doctors anymore, but desire treatment wherever and whenever necessary. Nonetheless it has to be ensured that the right treatment is provided. This requires instant access to information without prior knowledge of previous medical services that might have conducted. The ultimate goal is to enable access to a citizen's electronic health record or a targeted extract from it from everywhere and anytime in Europe [Pu06].

The current trend in many European countries is to build up **patient summary** records due to the fact that building up comprehensive medical records is hard to achieve at this stage of introduction of information and communications technology (ICT) in the healthcare sector [Va05]. This summary may be used for several purposes, e.g. to make

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[4] By the end of 2008, the majority of all European health organisations and health regions (communities, counties, districts) should be able to provide online services such as teleconsultation (second medical opinion), ePrescription, eReferral, tele-monitoring and tele-care. [CEC04]

[5] The RIDE project: a Roadmap for Interoperability of eHealth Systems in Support of COM 356 with Special Emphasis on Semantic Interoperability. http://www.srdc.metu.edu.tr/webpage/projects/ride

[6] The I2Health initiative: Interoperability Initiative for a European eHealth Area. http://www.i2-health.org

[7] The SemanticHEALTH project, Sharing Knowledge in e-Health information systems: A Semantic Interoperability RTD Roadmap. http://www.semantichealth.org

[8] The COCOON Project: http://www.cocoon-health.com

information available for unexpected contacts, or to comply with shared clinical pathways. The header of the summaries may include identification data on the patient and data on the next of kin, the clinician and the insurance. The body of the summaries may include various sections: history, allergies, active problems, test results, medications [Ro06]. All this information is coded following specific medical terminologies, such as SNOMED [SCC97] or LOINC [LOINC], and each country is defining its own structure for the patient summary. There are some supra-national initiatives to define a common patient summary such as HL7 CRS[9] and HL7/ASTM Implementation Guide for CCD[10].

An infrastructure for supporting a European Patient Summary demands a good level of interoperability among existing patient summaries, including the definition of the standards that need to be implemented, the technology adopted and the legal issues to be considered for the secure treatment of citizens' data. The EC interest in a European Patient Summary is focused on providing a virtual common infrastructure for accessing critical citizens' health data with respect to interoperability, multi-lingualism and security-privacy compliance issues. Such a summary can be written by any authorized healthcare organization around Europe and can permit all EU citizens to feel free to move around Europe, assuring them that authorized healthcare organizations will be able to easily and securely access their health data stored in the summary.

This paper describes the benefits that an infrastructure based on Triple Space Computing (TSC) [FE04] can provide for supporting the interoperability issues required by a distributed European Patient Summary. Chapter 2 reports the most popular interoperability standards for eHealth, highlighting their major drawbacks if used for a European eHealth infrastructure. Chapter 3 introduces the main concepts and advantages of TSC. Chapter 4 motivates the choice of patient summary as use case scenario for validating the TSC infrastructure. Chapter 5 concludes the paper summarizing the main advantages of TSC in addressing the European Patient Summary.

2   Interoperability Standards for eHealth

A powerful integration technology, which allows for immediate access to distributed information, is needed in order to provide healthcare organisations with a complete array of patient information. A number of standardization initiatives are progressing to address this interoperability problem such as:

- HL7 (Health Level Seven) [BHR99], a non-profit, ANSI accredited Standards Developing Organization, founded in 1987, that provides standards for the exchange, management and integration of data to support patient clinical care and the management, delivery and evaluation of health care services;
- GEHR/openEHR [EHM06], an initiative that fosters electronic health record (EHR) interoperability started in 1992 as the "Good European Health Record" EU research project that is currently maintained by the openEHR Foundation;

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[9] CRS: Care Record Summary http://lists.hl7.org/read/attachment/68278/1/crs1-4.pdf
[10] CCD: Continuity of Care Document http://www.mohca.org/pdf/CHMccrCHIT.pdf

- CEN/TC 251 [ESHI06], the technical committee on Health Informatics of the European Committee for Standardization, that, since 1998, is standardizing CEN EN 13606 / EHRcom [EC00, EC04]; and
- IHE (Integrating the Healthcare Enterprise) [Ve02], a not-for-profit initiative founded in 1998 that does not develop standards as such, but selects and recommends an appropriate usage of existing standards for specific use cases, stimulating the integration of healthcare information resources.

Most of those initiatives have been active for more than a decade and, after a first attempt in specifying the format of each message that can be exchanged among any pair of systems (e.g., HL7 v2.x [HL05]), they realized the need to derive messages and interaction patterns from a common shared conceptual model.

In 1999, CEN/TC 251 was the first to introduce, with CEN ENV 13606 / EHRcom, a list of machine-readable terms to be used for structuring EHR content. The standard defines an EHR information model and a modelling approach for deriving concrete interoperable messages to be exchanged between heterogeneous EHRs. However, the single-level modelling approach, the large number of optional fields and the high level of abstraction limited market uptake.

GEHR/openEHR in 2002 moved a step forward proposing the archetype concept [Be02] and the respective two-level methodology. The first level specifies a health care domain reference model [BH03, BHK05] that contains concepts such as role, act, entity, participation, observation, etc., while the second level specifies health care and application-specific concepts such as patient, general practitioner, and lab result, modelling them as archetypes. Each archetype constrains a set of concepts in the reference model (e.g., "Observation") to a specialized data structure (e.g., "Blood Pressure") and defines the vocabulary, such as SNOMED [SCC97] or LOINC [LOINC], to be used within instances of the archetype. The formal language for expressing archetypes, introduced by the openEHR initiative, is the Archetype Definition Language [BH05].

An alternative approach is offered by the HL7 Reference Information Model (RIM) [RIM] which is the ultimate source from which all HL7 v3 protocol specification standards [HL05] draw their information-related content. The RIM model is an explicit data semantics model by which the messages can be implemented locally and top-down, emphasizing reuse across multiple contexts. Moreover, RIM offers formalisms for vocabulary support that permits obtaining domain equivalent concepts among different terminologies (such as SNOMED, LOINC, etc.).

2.1   eHealth Standards Drawbacks

The eHealth interoperability standards are based on a message-exchange communication paradigm that has proven efficient and effective for certain activities in this area (i.e., hospital administration), but has shown some problems for effectively and seamlessly collecting and integrating data from electronic health records. When addressing such a need, there are at least two possible solutions with current ICT technologies. One possible solution is to build **centralized databases** that would contain all the medical

records of every patient. These would have to incorporate all of the different access rules and policies regarding different users and different levels of access. This kind of efforts has **four weak points**:

- the hardware and maintenance *costs* of a such European centralized infrastructure could became untreatable if managed by a unique central entity;
- the centralized repository approach creates *competitive* and *security issues* about who controls and has access to the information on a specific patient;
- the *difficulty in maintaining an up-to-date repository* originating from a large number of independently evolving systems; and
- a message once sent (especially in an asynchronous scenario) gives the owner a *sense of disengagement instead of* strengthening the sense of *ownership* due to the fact that the data become stored under the ownership of another entity.

Another possible solution, which is nowadays widely adopted in hospitals, is to **exchange messages** among different department information systems (such as RIS[11], HIS[12], PACS[13], …) **only when necessary**. In this way no central repository is required since every system has it own local repository and the ownership of the data seems respected. But this solution also has **several weak points**:

- each recipient must *know in advance which systems need to receive the information* and *where to look for information*;
- each recipient must *know in advance the terminology* (e.g., SNOMED, LOINC) *to use* when communicating for a specific record content;
- each recipient ends up maintaining *a specific interface for each other system* it has to interact with; and
- *data mining* (for epidemiological studies, disease prevention, early diagnosis, pharmaceutical research, enhancement of patient safety) *becomes almost impossible* due to the large amount of messages to be exchanged.

A quick comparison between centralized databases and message-based systems highlights that the weak points of the first are related to the high cost of maintenance, complexity and availability of the central database, whereas the latter suffers from functional problems related to the scattering of data.

3   Triple Space Computing and the TripCom Project

Triple Space Computing (TSC) is an innovative paradigm [Fe04] that is taking a significant move towards a new era of the Internet. As reported on the website of TripCom [TripCom] - the leading European project in this area: since the invention of the Internet in the 1960's, the two major evolution steps were email and the Web. Email changed people's communication processes by providing instant communication over any geographical distance in an asynchronous fashion based on the message-exchange paradigm. The Web changed people's communication processes by providing instant publication over any geographical distances in an asynchronous fashion. It is based on

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[11] RIS: Radiology Information System
[12] HIS: Hospital Information System
[13] PACS: Picture Archiving and Communication System

broadcasting via persistent publication of information. So, the two major asynchronous styles of human communication (direct communication via mail and indirect communication via publication) have been significantly improved through email and the Web.

	Message	Publishing
Human Net	eMail	Web
Machine Net	So-called Web Services	Triple Space
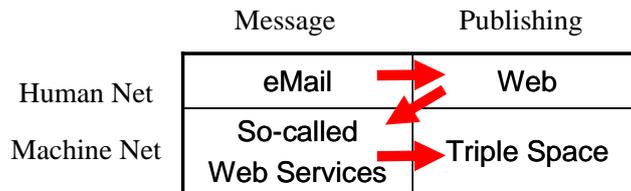
Figure 1: Evolution of communication means for humans and machines as presented in [KHP05]

TSC [Fe04, KHP05] asserts that the next step for the Internet is likely to be the direct integration of applications and computers via Web service technology. This network no longer directly interlinks humans but interlinks applications and programs to provide integrated services to the human end-user. However, current Web service technology has very little to do with the Web. It is based on the message exchange paradigm, similar to email communication (see **Figure 1**).

Realizing this vision and a new technology is the mission of TripCom with the result being the integration of Tuple Spaces [Ge85], the Semantic Web [BHL01] (based on the triple-based data model of RDF [KC04]), and Web service technologies (see **Figure 2**).
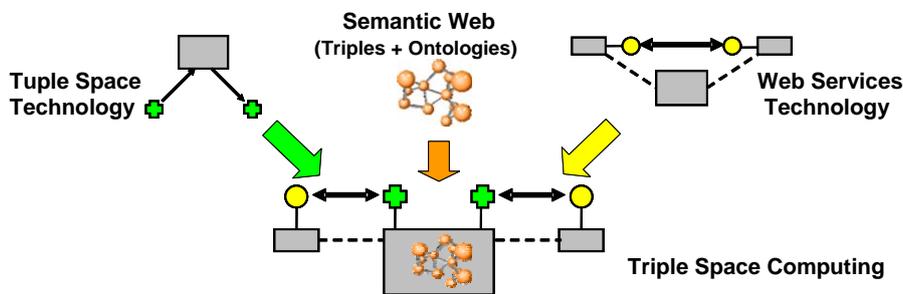
Figure 2: Triple Space Computing results from the integration of three existing and well known technologies

To this end, TripCom plans to improve Tuple Space technology by adding semantics for data and metadata in a scalable and linkable Triple Space architecture, thus allowing for more powerful data retrieval than current systems. TripCom also plans to improve Web service technologies by adopting the flexible and powerful asynchronous communication and coordination model of Tuple Spaces and Virtual Shared Memory technology [Ku01]. It also intends to improve business data exchange standards, solving typical integration scenarios by making use of ontologies and data mediation [MCS05] and to demonstrate the usefulness of this approach in several practical use cases. Finally, TripCom plans to establish a suitable security, privacy and trust model for the Triple

Space to ensure secure communication and data handling. As the result of the project the combination of these building blocks could give ground to a novel Semantic Web service paradigm.

In summary, TSC aims at offering an infrastructure that scales conceptually on an Internet level. Just as the Web supports the publishing of Web pages for people to read, TSC supports publishing of machine-interpretable data. The main advantages in TSC approach, with respect to current message-based solution are:

- **time autonomy:** providers of data can publish data at any point in time even if subscribers are not on-line;
- **location autonomy:** since the data resides in a virtual space, there is no need to know which physical node stores the information. Once published, the data becomes independent of a provider's internal storage (thus available even if the provider is not on-line) and data is both written and read locally by subscribers even though it is globally distributed among nodes;
- **reference autonomy:** providers are independent of the knowledge about potential readers and security rules can be expressed to be sure that only authorized parties can read or write particular data; and
- **schema autonomy:** the data are represented independently of any provider's internal data schema since data mediation engines [MC05] permit automatic alignment and re-use of information written following different standards and different languages.

The time and reference autonomy features of TSC come from the use of a virtual centralized space whereas the location and schema autonomy features are results of the adoption of a combination of Semantic Web and tuple space technologies.

4 Triple Space Computing for Sharing Healthcare Data

TSC may provide an innovative solution to health and medical data sharing among heterogeneous, distributed environments, because it is focused on persistent publishing of knowledge (information augmented with semantics) and not only its collection and distribution. Such a new technology will allow authorized users to identify which health care data is available in order to access it when necessary (e.g. authorized physicians will have a complete view of the treatments their patients are receiving, which is very important for chronic diseases as diabetes).

The TripCom use case on eHealth aims at providing requirements for sharing health data in triple spaces and subsequently stressing the TSC infrastructure evaluating its capabilities and advantages in eHealth scenarios. To address this goal, the use case to be chosen should:

- **be well defined**, avoiding the temptation to solve a too generic problem;
- **highlight the requirements** that stress the TSC interoperability and security features;
- **not be easily addressable by existing approaches** (such as common centralized databases or message exchange) because of the intrinsic complexity of the required technology;

- **encourage the dissemination** of results providing European researchers with a new technology infrastructure that can really emphasize the capabilities of the TripCom approach and its abstraction layer for interoperability and security.

We believe that the **European Patient Summary** represents a suitable starting point for the activities of the eHealth use case because:
- it is a **well defined** scenario with specified requirements;
- it involves not only socio-economic and legal aspects among member states (which will be addressed in other projects such as RIDE or SemanticHEALTH) but it also **demands complex technology requirements** about eHealth systems interoperability and security restrictions on the treatment of citizens' data;
- these **requirements are not easily addressable by existing technologies** due to the strong need of a distributed environment for sharing data and services (such as the difficulty to have synchronised knowledge about a patient with the source of information);
- it is a current European research trend and the experience grown up will support the **sharing of best practices and experience across other projects** on TSC technical capabilities and with EU research activities on technical aspects of eHealth interoperability solution.

An electronic health record stored in a triple space repository would avoid most of the drawbacks listed in Section 2.1:
- standard TripCom infrastructure would be utilized aiming at Internet scalability which is a key requirements for an European eHealth system;
- security would be handled by standard TripCom security and additional security features would not have to be patched onto the system;
- updates would be the same whether they came from one or multiple providers;
- the data provider would treat the data the same as existing internal records;
- users would know where to look for data;
- data mediators would automatically convert between terminologies instead of requiring to individual users to do so;
- users would know where to look for data and will use a single interface to the system that has data mediators written to convert each external system to a common (semantic) form; and
- data mining would be easy for systems with access permission and such permissions could be designed so that data mining would not have access to personally identifiable data, but would be able to aggregate data.

The autonomous features of TSC are exactly what a European Patient Summary would require:
- **time autonomy:** in order to almost ensure ubiquitous access to medical information, each medical care provider needs to be able to store data and retrieve it at any time even if a prior data provider is currently not available;
- **location autonomy:** the patient summary space becomes a virtually closed unit of information since all medical institution participating in a given space for the patient summaries provide parts of the logic and parts of the storage.

Distributed physical copies of the data help guarantee access even when individual sites are not connected to the Web. Data needs to be accessible to medical providers, even if the party which generated the data is not online (or even still in existence);

- **reference autonomy:** medical care providers do not know what other provider may care for a patient, and thus need the data, in the future. Even in the case of terminal patient care, they would not know of parties which may require future data mining. Access to medical information source must hence be fully decoupled in reference; and
- **schema autonomy:** each medical care provider may continue to use their own internal schema and vocabulary. The TSC data mediator will convert data to and from that schema as appropriate. Moreover, the use of semantics allows computers to support practitioners in faster and better extraction and evaluation of relevant patient data and hence ensures improved treatment of patients independent of political and socio-cultural boundaries.

In summary, these properties enable the implementation of a novel kind of architecture avoiding the drawbacks of centralized databases and message-based systems identified in Section 2.1. The TripCom approach will provide a virtual view of a single information space and, at the same time, will reduce complexity of administrative tasks. While providing a highly scalable solution is regarded as one of the main responsibilities of triple spaces, the participating institutions are responsible for keeping their own data up-to-date. Further, this approach permits integration of temporarily connected systems that wish to supply non-critical services [KBM05] and provides a powerful tool for data and process integration that is strongly required in eHealth scenarios.

5   Conclusion

TripCom activities in eHealth area will aim at evaluating the capacity of TSC to address the European Patient Summary scenario. TSC may represent an innovative technology factor that partially supports the realisation of the vision since it can provide a wide, trustable and confidential access to information distributed in a large number of heterogeneous health records. The TSC infrastructure provided by TripCom will present these strong points:

- **it will be a realistic solution for the data ownership problem** because healthcare organizations will not loose their control over resources and they will be able to share information only with those that are authorized as requested by the patient summary,
- **it will provide a simple way to guarantee consistency** as health data will be handled by a virtually centralized repository and neither physically transmitted to other systems nor copied to different local repositories. The data is simply published in the virtual space and used when necessary,
- **it will supply a straight forward way to deal with integrity** because data will not be transmitted directly to other systems but managed by a virtually centralized repository and it should be impossible for anybody, but the owner or authorized users, to add data accordingly to legal policies,

- finally, **it will be a cost-effective solution** because additional storage resources (and related management cost) are drastically reduced and can be better distributed over the whole of the European Union.

As stated in Section 1.1, some European initiatives are currently working in eHealth scenarios to support the EC in issuing the recommendation on European eHealth interoperability planned for 2007. Even if the first prototype implementation for TSC is planned for early 2008, TripCom activities in eHealth intends to actively contribute to the EC initiative by providing a cost and benefit analysis of developing a patient summary over TSC for the begin of 2007.

6   Acknowledgements

7   References

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