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The Data Challenge for E-Health

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Questions about healthcare data access and sharing on the one side, and security and privacy on the other, are integral to debates about European e-Health.

In technical terms, there is also a need for data management, issues of data entry, access and storage, and this at a multitude of levels – from patients through doctors through hospital administrators to parastatal organisations and, finally the State. All this is not really final – as there is/will be a need for coordination at both the EU and international levels.

One opinion leader in this context is Patrice Blemont, Director of the Regional Agency of Hospitalisation for the Franche-Comté region in France.

HITM interviewed Mr. Blemont on his perspectives about the DMP, France's shared medical record project and other e-Health initiatives, especially with regard to the challenging question of databases.

HITM: France seems to have chosen a 'head-on' approach to facing the inherent health informatics challenges of emerging e-Health programmes and the consequent debate on the complex ethical/legal issues involved. We hear a lot about the projects, but the DMP (the "shared medical record") seems to be one of the cornerstones. What is the current status and timetable for implementation?

Patrice Blemont (PB): After the 2007 Hospital Plan for information technology and the new 2012 Hospital Plan which entails investments in the region of 1.5 billion euros, we can say that France is now clearly en-route towards the modernisation of its healthcare IT systems.

The DMP has been legally ratified since March 2004. It, alongside a variety of other projects such as T2A, the Vitale 2 card, secure remote transmission, etc.; are all catalysts for the process of modernisation.

Some regions such as Franche-Comté contribute a great degree to the modernisation process by virtue of its regional healthcare platforms that serve as the medical data repositories for all healthcare professionals in a certain region.

The implementation of a regional platform is integral to providing patient care continuity. It is a necessity within each region and its organizations, to prevent any interruption to the sharing of medical information between healthcare professionals.

HITM: Do you agree with some assessments of France's hospital IT expenditure to be among the lowest per capita in the EU? Or are there statistical issues involved?

PB: Even though the percentage of investments in healthcare IT by hospitals seems relatively low, it should be noted that certain expenditure categories are not always included in the statistics and are therefore not integrated into the budget of IT managers. If one takes into account investments in related technical fields such as telephony and/or biomedical technology; we, without a doubt, achieve a higher, more realistic, view of the level of investment.

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In recent years, these have begun to be consolidated under the heading of "IT" – investments in areas such as voiceover- IP (VoIP), imaging, etc. The 2012 Hospital Plan targets information system investments in France to approach 3%, which would bring it well into line with the EU average.

HITM: According to a White Paper from Lesiss in 2006, only 10% of French healthcare facilities had shared patient records at the hospital level – while 30% had partial sharing?

Do you see the low penetration level of the former (the *acquis* if you will) as an advantage?

PB: In reality, it may make a compelling case to start from scratch and build up a wholly new approach to data sharing, which in turn would centre on a global approach to healthcare information systems. However, one can also point to the communication limitations of present-day IT systems.

Focusing efforts on data acquisition is of the utmost importance and specialized tools are already available to meet these needs. Effective data acquisition and the ability to efficiently and flexibly deal with the complexity and scalability issues inherent in a data sharing project are the key factors to a project's success, as are general change management and the ability to adapt to the requirements of medical staff.

HITM: Technically, we see some key problems at the database level: the question of data definition. Medical data is sensitive by definition, access is often time-critical for patients and efficient healthcare delivery – this can conflict with issues of privacy and ownership (individual versus collective, public versus private).

PB: Our strategy is based on a centralized clinical data repository approach. This repository is located within the regional healthcare platform.

As a result, we have sought to reach a maximum of data availability in a Regional Data Centre. This solution has numerous advantages. Totally distributed architectures make it far harder to ensure that all data sources can be accessed and available at any given moment.

Finally, we cannot have direct and open access to databases since this would compromise security. Thus, it would become necessary to duplicate data entry. As a result, this increases costs on one hand and continues to leave security issues as a challenge.

We made the decision to use the technology from a company called dbMotion which offers the possibility of having a mixed approach - of a regional data centre, fed from one side by certain agreed/endorsed systems and then, when and where necessary, distributed databases connected to this central repository.

HITM: So, overall, you are in a technically complex, politically-charged and fast-moving business. Do you have any comments – especially on the popular buzzword interoperability ?

PB: Interoperability is core to our strategy. Since 2000, we have made architectural and technical decisions in Franche-Comté inspired by the global IT community (eg. XML, HL7 with EJB, SOAP connectors). In 2004, we implemented an IHE Pix profile for the first time for patient identification reconciliation; in 2006 we followed with IHE XDS for our repository.

HITM: In the above context, what is your opinion regarding the dbMotion Solution that the Franche-Comte region has officially adopted? Any limits to its adaptability? Scalability?

PB:The dbMotion Solution has many positive benefits, but for our purposes two are of primary significance. The first is its proven ability to provide a field-proven DMP (shared medical record) on a national scale. The second is its practical approach to health information exchange in terms of its rapid presentation of a unified real-time view of the integrated medical record derived from disparate and diverse IT environments; a record that can be either shared or personal.

What we still lack is the familiarity and understanding of what is exactly meant by the concept of the national "DMP" in France. This would enable us to further reduce some of the major concerns expressed, especially among physicians, about the incorrect use of data sharing. Incidentally,

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the legal framework to protect data security and patient privacy in France is already in place to prevent any abuse of the system.

The dbMotion Solution also offers very advanced functionalities at the level of access rights management and data confidentiality, which allows us to implement operational aspects of the current legislation.

HITM: So there are technologies that can integrate distributed data, do this in near-real-time and still provide security?

PB: As mentioned, the data repository in our region is based on IHE XDS which was developed by one of our partners - SQLi. This repository was implemented within the framework of a regional interoperability platform that enables the connection of various regional healthcare organizations. In order to extend this platform, we are leveraging the strength and power of dbMotion's solution and the company's experience with large-scale medical information sharing implementations. A key factor to the Franche-Comté project's success will be its ability to move quickly and to share competencies on common technical platforms, not only in terms of technology but also between key suppliers.

The auto industry, for example, faced such challenges, and carried out a number of joint developments, which has not stopped vendors from subsequently competing for the same market share.

HITM: Any comments on the French versus UK approach in these areas – basically incremental versus Big Bang. Do you think the French approach has more user/physician involvement upfront, and is likely to build positive consensus amongst all concerned?

PB: There are indeed significant differences between the approaches. In France, the DMP (shared medical record) project's many individuals and organizations involved in its development have had to overcome the multiple differences in philosophies and approaches, especially within the steering committee for the DMP; all the while maintaining transparent processes – not an easy task.

In France, it is not only representatives from the user community but also medical bodies such as the DHOS (the French Health Ministry's Hospital Directorate), representatives from public and private federations, the CNIL (National Commission on Data Protection), etc., who have been involved.

From outside, this may all look somewhat chaotic, but I have to say that the story is rather different from inside. In Franche-Comté for example, there are a great number of working, technical and medical groups that have been able to discuss this project and reach a consensus.

In turn, such groundwork has permitted the State to invest significant sums in precisely-targeted e-Health projects (health files, telemedicine, DMP, etc.). I am convinced that given such clearly identified objectives, healthcare professionals are left in no doubt about the need for modernising our system and enabling efficient healthcare delivery in the best interests of the patient.

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