IT Volume 3 / Issue 1 - Winning Project

The Health Information System

Regional Cancer Network Director, SISRA

Contributors: P Biron, H Spacagna, P Castets,

T Durand, P Dureau, JP Descombes, A Deblasi,

P Vandenbergh, T Philip, F Farsi.

SWORD, France

Lyon, FRANCE

biron@lyon.fnclcc.fr

In order to improve the quality of patient care and faci litate rapid treatment, the Saarland University Hospital decided in 2002 to optimise the process of eva luating clinical findings and eliminate weak optimise the process of eva luating clinical findings and eliminate weaknesses nesses in analogue dictation using tapes. Thus, we want to briefly summarise the managers interested in the outsourcing of IT functions.

The aim of SISRA is to contribute to better health services for the population by proposing each caregiver and each health professional with a number of regional tools. SISRA first provides a regional patient identification number as no

nation-wide national health ID is currently available in France. SISRA also allows medical data sharing through the shared and distributed patient record and offers several tools for care coordination. Three major principles have driven SISRA since its launch: Respect of Human Rights, development using a bottom up approach and avoiding intrusive EHR integration. Realisation has been fully supported by industrial partners. To date, SISRA connects 55 hospitals, both public and private, representing one third of all regional healthcare facilities, and 66 % of hospital beds. Founding partners are the three University hospitals of Lyon, Grenoble and Saint-Etienne, the Comprehensive Cancer Centre Léon Bérard, the regional cancer network ONCORA, and a private practice association (ADSIMIL). SISRA is politically influenced by the full college of regional health representatives, and the umbrella organisation of patients' associations (CISS-RA).

I- The System and its Deployment

SISRA uses a combination of backbone tools.

> STIC (Serveur Télématique d'Identité Communautaire) is a regional patient ID server that provides local identification solutions and relies on five hard characteristics: family name at birth, first name, sex, date of birth, and postcode of place of birth.

> DPPR (Dossier Patient Partagé Réparti) is a "shared and distributed patient record". "Distributed" means that the information is not stored centrally but is available from each local repository. Working like a web-based "health search

engine", the system provides real-time access to original medical data documents, including hospital discharge letters, surgery reports, histological reports, lab results, treatment strategy, radiology reports and DICOM images.

> PEPS (Plateforme d'Échange entre les Professionnels de Santé) is a health information exchange platform developed to serve 3 functions: PEPS NETWORKS to collect and centrally store all structural clinical information shared within a given network; PEPS HEBERGEMENT / HOSTING to connect healthcare facilities not yet equipped with a consistent

EHR system; PEPS VILLE / COMMUNITY to collect clinical data from GP's EHR systems not operating continuously, nights and weekends for instance.

From these core systems, allowing to share medical data across several sites, different tools have been developed to facilitate care coordination.

About ten applications have already been developed from this structure, in fields such as emergency, oncology, perinatal care, etc… Two of them are intensively used.

> TRAJECTOIRE is an equivalent of the region marketplace for hospital beds. The system provides a list of options in which appropriate follow-up treatment (e.g. nursing, rehabilitation…) corresponding to the patient's needs can be provided.

> DCC (Communicating Cancer Record) is an oncology-specific disease record. It was created with the double aim to provide both healthcare providers with oncology-specific data selected from the patient's electronic medical record and to help health professionals organise their own

activities. Functionalities include:

> Directories of regional decision-making centres;

> Planning of multidisciplinary oncology consultation;

> Completion of oncology specific files allowing to determine the best treatment strategy during these consultations, in accordance with good clinical practices;

> Provision of personalised treatment plans for each given patient;

> Notice of the decision to the general practitioner referring the patient, and

> Evaluation of the activity of the centres.

Up to now 72 data repositories have been connected, bringing together 54 health facilities, 8 cancer coordination centres, 7 health networks for cancer, pain management and palliative care and neonatology, and 3 private emergency care units.

SISRA already stores 1,500,000 regional ID patient records corresponding to 25% of the Rhône-Alpes po - pulation, and 400,000 regional patient records (DPPR), with more than 4 million medical data. More than 30,000 connections are observed each month, with 400,000 accumulated accesses. "Trajectoire" now facilitates finding 80% of follow up beds in the region. More than 50% of other French regions have adopted the system, making "Trajectoire" the leading system in France in this field.

II-Success Factors

First and foremost, we have given special and pragmatic consideration to the users' needs. Analysis was based on real pragmatic and medical needs of the users, taking into account traditional ways of organising data, processes, and the computerization level of patient records (paper or computer).

We also wanted to elaborate an exhaustive record: 100% data for 100% diseases and 100% patients. Since the choice of medical data to be accessed is made by the searcher and not the sharer, special attention was given to data hierarchisation and classification. We have opted for internationally recognised tables and built upon previous work performed in the frame of the French national electronic record. Given that every practitioner and health facility must archive their own medical files, and considering the economics of storing data, especially with the heavy weight of current DICOM images, it was decided that data would remain stored in the repository of each data owner, avoiding double data entries whenever possible. A major roadblock was the heterogeneous computerization level of the different health facilities: Out of 300 facilities in the Rhône-Alpes region, only 48% used computerized patient records, while 52% still used paper records.

Human and political factors also played a key role in the project's success:

> Since the beginning there has been a strong commitment from all major regional regulatory authorities: Regional health agency, regional council and liberal medical practice organisations, leading to funding agreements.

> The energy of the founding members of SISRA was as strong as their desire and ability to work together and pool their capabilities.

> There has been an effective integration of health user representatives into the process. SISRA is a very small coordination unit with no full-time employee. However, personal commitment from each founding member, and clear, distinct and well-articulated roles and responsibilities have made it possible.

SISRA has designed workgroups and tools but relied on industrial partners for development and integration tasks.

Each project relied on strict sequencing, with precise separation and articulation of each step and event. Step 1: The steering committee decides on a collective view of what should be done according to its health policy. Step 2: The operational committee identifies professional and technical skills and then designs, elaborates and finally organises the implementation of the tools in a limited area. Step 3: Back to the steering committee-regulatory authorities include the operative project in their strategy and become its principal sponsors; they ensure its generalisation and stronger implementation.

Lets examine the example of the DCC (shared patient record in oncology). Step 1: The French cancer plan recommends that every patient's case be discussed in multidisciplinary onco - logy consultation. Funds provided by national regulatory authorities (INCa) were raised. The management of the project was entrusted to ONCORA, the regional oncology network.

Step 2: The major problem was the technical complexity of the project due to the existing situation where some institutions provided the information through their own system, and some were already involved in common webbased applications. However, we were able to elaborate a powerful communication tool serving as a viable solution for institutions where no system has been developed, a complement to pre-existing hospital information systems and a replacement of existing web-based systems. Several pilot units were designed to test the feasibility of the project.

Step 3: Generalisation after feasibility evaluation and conclusion by the steering committee that the project was technically effective. The regulatory authorities became involved in the generalisation step in June 2009. They finally ordered, in a letter to the directors of all healthcare facilities, that 100% of the patient ca ses discussed in multidisciplinary oncology consultations should be recorded in the regional system by the end of 2009. Approximately 52% reports are recorded at this stage.

Previous experiences of sharing data within a hospital or network have shown that to develop access and use a large amount of data is required: Number of patient EHR, number of available medical data, especially key data like biology, functional explorations, or DICOM images for me dical decision making etc. Searching data in the system and not being able to find it can be rapidly discouraging and limit its use. Practitioners will then still prefer traditional channels like letters, fax and phone. Enlarging the amount of data requires the connection of many repositories.

From an historical point of view the building of the system is a long lasting task. It began between 1995 and 2000 with planning, testing and learning from previous isolated experience, and identifying cornerstones like the need for a unique patient ID, and system accessibility, reliability and security. The second phase, from 2000 to 2005, focussed on preparing connections between repositories and developing DPPR, STIC and PEPS. After a survey of the levels of computerization and use of local tools we began the development of connectors between the different local software editors. In 2005, the political objective was to have 50 repositories connected by the year 2009, despite difficulties due to heterogeneity and lack of innovative technology and systems skills in small health facilities. The third phase currently underway was started in 2005. It aimed, firstly, to fill the DPPR with content, deploy the DPPR on pilot sites and then wider after creating a SISRA Deployment team, and secondly, after accumulation of sufficient content, to facilitate its use by the implementation of specific levers like care coordination tools allowing patient placement at discharge (TRAJECTOIRE), emergency help (SPIRAL, OURAL) or oncology management ("shared patient record in oncology"). For 2009, the political objectives are 100% finding of followup beds using "Trajectoire", 100% Oncology, Obstetrics and emergency reports in the DPPR. The next step will be to increase secure exchange through the DPPR (DICOM and second advices), messaging with the objective to eliminate all paper in medical exchanges, thus ensuring speed as well as improved quality and reliability of data and care. The political objectives for 2010 are to increase the use of the tools to all caregivers and facilities, for example to nursing homes, old people's homes.

Throughout the development of the project, consumers and citizens have been strongly involved; health consumers' representative associations (CISS of Rhône-Alpes) have been invited to participate in workshops concerning access authorisation, access controls, and access for any stakeholders to logs in EHR. At this point we can consider that there is no actual gatekeeper, and the patient is the only gatekeeper of his own record.

Furthermore, taking into account the tools in use and that the use of electronics in medical practice is also a tremendous change of behaviour and culture we have decided to give special attention to the accompaniment of the change. A specific team was set up in 2006 to develop tools for stakeholders, patients, local project managers including media communication (booklets, flyers, posters, TV film in waiting rooms), training and formation of trainers by e-learning, DPPR Training, tool-specific training (Oncology, Trajectoire). The team also ensured that all relevant documentation and statistics and annual reports for health facilities and professionals were available to the users through the SISRA dashboard.

III- Technical Choices

The security and confidentiality of health data is of first concern. The "distributed" model means that access to all data is difficult. We have chosen to enable access through a strong identification via a microprocessor Health Professional ID

Card and password, authorisations by the patients themselves, total traceability of information flow: Virtual Private Network, HTTPS following the French recommendations.

For EHR integration we have faced many difficulties as vendors were solicited for developing connectors for multiple projects, each time with specific standards". It was difficult at first to find volunteers, even when offering payment. The biggest difficulty lay with the IT managers of health facilitites who feared the intrusion into their own systems.

Consequently, we opted for a solution compatible with all facilities, whatever their computerization le - vel; an easy and non-intrusive EHR integration providing access to information in the form in which it is stored: PDF, DOC, XML, DICOM, JPG, etc. The connectors were developed by firms in charge of the local EHR (workload ~30 days versus 100 days for the first ones), by improving the local gateway, by providing industrial partners (local EHR vendors) with the SISRA API (Application Provider Interface). We have tried to have achieve integration with the GP's EHR: GPs visualise DPPR data in their local EHR (web services): one click to upload and one click to visualise. A SISRA local (DMZ) Gateway guarantees communication security. Today there are 23 connectors with health facilities EHR vendors corresponding to a potential of 92% hospitals (public/private) connectable and 5 connectors with GP's EHR vendors.

All SISRA tools are designed by SISRA teams but developed and integrated by industrial partners (SWORD, STERIA, ATOS). SISRA is the owner of the tools that are open source in terms of diffusion and provide an opening for better cooperation in tool improvement. For instance, in 2006, the first version of DPPR was taken up by industrial firms for the first trial of the national DMP in our region and further developments were integrated in the current version. To date, eight French regions have used the TRAJECTOIRE open source tool.

Based on an interface with local tools, SISRA encourages the computerization of healthcare facilities by leaving local managers free to choose the solution they wish.

All SISRA tools have obtained CNIL agreement. The CNIL (Commission Nationale Informatique et Libertés) is an independent French administrative authority protecting privacy and personal data. All SISRA tools give a unique technical answer to multiple applications: Information sharing, information exchange: word documents, numeric data or DICOM images, etc. Once a facility is technically connected to SISRA, the facility can share its local EHR with the

DPPR, can securely exchange documents with other practitioners, exchange DICOM images for second opinion or expert advice. All this by applying the same technical solution. SISRA guarantees regional healthcare facilities compatibility and convergence of regional tools with national projects: DMP, DCC, and OURAL.

SISRA has been audited by a consultant appointed by the European commission. It is one of 10 independent evaluations of good practice in interoperable electronic health record systems in Europe and beyond, commissioned by the European Commission with the aim to improve awareness of the benefits and provide new empirical evidence of the socio-economic impact of, and lessons learnt from, successfully implemented systems.

Annual net benefits have been achieved since 2008, five years after the first implementation of the system, suggesting an increasing and sustainable cumulative net benefit from 2011 (though 16.6 million invested since 2001).

The three major lessons from SISRA for future decision-makers and development teams are:

1. Plan on long time scales, they are realistic;

2. Build from previous successes, and

3. Contribute to the pre-existing strategic and operational goals for healthcare.

Interoperability and transferability is essential to SISRA's success

In conclusion, things work out over time. In France we say "Paris was not built in one day…" Guiding principles are to respect the IT choices made by each healthcare facility, use industrial solutions, keep in touch with the environment and develop a specific team to help the implementation. SISRA is a unique data capture and storage network, available securely and confidentially when and where needed. Over the past ten years, we have gone from a situation where there was nothing to get people to work together beyond their legal obligations, from a situation where potential users were on the reserve and only minorities used services, to today, when users are always asking for more services. Our goal is not only to develop tools but also to make them accessible to users by a steady accompaniment of change. Over these ten years, ambitious investment has been made, based on a light but dynamic policy and a determined steering committee, a pragmatic and efficient choice of computerization level, respect for the solutions proposed by the actors, and a constant assistance in project management. Finally, the system allows long-term time and cost savings in medical practice and public health and, above all, it is a way of increasing the quality of patient management.

Published on : Sat, 3 Jan 2009