Sainte-Justine Hospital positions itself for breakthroughs in pediatric research and treatment.

Overview

- ***Business Challenge***
  To realize the potential benefit of genomics in pediatric research, Sainte-Justine Hospital Research Centre needed to streamline the way it gathered, managed and updated the clinical information it relied on. Data fragmentation combined with manual processes led to wasted resources and a longer research cycle.
- ***Solution***
  Sainte-Justine teamed with IBM to transform its existing infrastructure for integrating patient information into a powerful research support tool. Automated workflows keep clinical databases up to date, enabling the hospital to channel more of its efforts and resources to core pediatric research.
- ***Key Benefits***
  - *Expected 90 percent reduction in time required to gather research cohorts*
  - *Expected 75 percent reduction in administrative costs associated with data gathering and validation, which Sainte-Justine can channel into core research efforts*
  - *Faster development of new treatments for complex pediatric diseases*

Established in 1907, Sainte-Justine Hospital is the largest pediatric hospital in Québec and the second largest pediatric hospital in North America. Sainte-Justine Hospital's Pediatric Research Centre is well known for its work in such pediatric diseases as childhood leukemia and other complex pediatric diseases.

Behind most every medical breakthrough is an enormous body of research, much of it taking years to compile, analyze and translate into new and more effective treatments for patients. Not surprisingly, the clinical research process is often characterized as a search for hidden clues or patterns within a vast pool of biomedical data. The recent emergence of genomics as a primary tool for researchers, and the successful use of ultra-powerful computing resources to spot genetic patterns in diseases, have reinforced the notion that the key to medical research is unlocking secrets in the data.

> *"With IBM's assistance, we have vastly increased our ability to exploit the knowledge of the human genome in the way we understand and treat pediatric illnesses."*
>
> – Dr. Daniel Sinnett, head of the Oncogenetic Research, Sainte-Justine Hospital Research Centre

Business Benefits

- Expected 90 percent reduction in time required to gather research cohorts
- Expected 75 percent reduction in administrative costs associated with data gathering and validation, which Sainte-Justine can channel into core research efforts
- Improved information accuracy and the elimination of duplicate entries
- Faster development of new treatments for complex pediatric diseases
- Optimization of existing pediatric treatment practices to maximize responsiveness and minimize side effects
- Improved ability to secure research funds and expertise

"All research projects will eventually be supported from a single database and integrated infrastructure. And starting now, our physicians can access data in a way suited to their specific needs. This provides long-term follow-up with patients well into adulthood."

– Dr. Daniel Sinnett

But if you talk to the people actually engaged in the process – from senior researchers to technicians to administrative personnel – the odds are good that they'll view their biggest challenge as obtaining and validating the base of data needed to do the research. Standard research practices revolve around the tracking of groups of patients with common attributes or clinical profiles, known as cohorts. Depending on their focus, researchers' data needs in establishing a cohort can range from family health information to genetic profiles, test results and treatment histories. All too often, obtaining this information requires researchers to extract information from patients' paper-based files, in some cases spread across different departments. This tendency for critical information to live in "pockets" throughout the hospital has in effect created a structural bottleneck in the research process, which not only draws precious resources from hospital staff, but also lengthens the time required to develop new and more effective treatments.

In the realm of pediatrics, these challenges are amplified by a number of factors. For one, the pediatric illnesses targeted by researchers are by comparison quite rare, making it harder for researchers to assemble a cohort to study them. An even greater challenge relates to the inherent complexity of understanding the dynamics of pediatric illnesses, since their onset and progression tend to coincide with major metabolic and physiological changes in the children themselves. As a result, pediatric researchers are especially dependent on patient data points gleaned over a long time horizon – starting as early as their mothers' prenatal care and extending as far as years after their treatment – to understand the interplay of factors involved in pediatric illnesses. The combination of small cohort populations and the need to track them consistently over time place a heavy burden on hospitals like Sainte-Justine Hospital Pediatric Research Centre, which are dedicated to pediatric research.

End of the rainbow

A teaching hospital affiliated with the University of Montreal and the second-largest pediatric hospital in North America, Sainte-Justine (www.recherche-sainte-justine.qc.ca) had been the first hospital in Québec to implement an electronic health record (EHR) solution. Developed by IBM Canada in an initiative known as "Project Rainbow," the solution was designed to provide a framework for Sainte-Justine and two sister hospitals to share patient information and improve the quality of care and the patient experience. In the wake of this highly successful engagement, Sainte-Justine and IBM sat down to establish a roadmap that would build on the new capabilities that resulted from the project, chief among which was the ability to gather and aggregate a wide variety of clinical information. While its EHR solution was designed to serve the clinical side of its operations, Sainte-Justine and IBM realized that the integration infrastructure that lay at the heart of the solution could be extended and adapted to vastly improve the efficiency of the hospital's research operations.

With advances in genomics changing the face of medical research, Sainte-Justine saw both the need and the opportunity to take its research capabilities to the next level. Although Sainte-Justine viewed advanced computing technologies as a key part of this transition, it recognized that the most fundamental change would be in resource efficiency. Put simply, streamlining and automating its "front end" processes would enable Sainte-Justine to channel more of its scarce resources into the core research activities.

With the electronic health records solution as a starting point, IBM needed to create a technology and process framework on top of it that would perform all of the updating, validation, security and patient authorization functions necessary to use the valuable data. In addition to medical data drawn from hospital records – such as tests and records of treatments – the solution also needed to incorporate genotypic data drawn from patient tissue samples. This combination was essential to understanding not only the genetic basis of disease, but also how genetic makeup could affect the way a patient responds to a particular course of treatment, or the likelihood of a patient experiencing side effects from a particular treatment. Lastly, IBM needed to create a powerful, flexible and easy-to-use interface through which researchers could analyze or query the data.

Following a new flow

Led by IBM Global Business Services, IBM developed a solution that meets each of these requirements. From a process perspective, the starting points are the many clinical systems throughout Sainte-Justine that generate patient data. Each time a patient's information changes, the information is automatically sent to a gateway that serves as a hub to all the hospital's clinical systems. Once a patient's record reaches the gateway, an information broker (powered by IBM WebSphere Business Integration) employs a series of business rules to filter, process and compile the information. The first function is to check the patient's file for parental consent, which is stored as an electronic signature. If the consent is not on file, the information is automatically discarded. If the signed consent is on file, the solution then locks in the patient's privacy by replacing the patient's name with an anonymous global patient identifier that remains attached to the patient and – importantly – can be traced back if a new treatment is found. The broker's final function is to extract pre-specified data elements (such as blood count) from the overall record, and to send those elements to a master patient record stored in an IBM DB2 database running on an IBM System p5 570 server. Each time a patient undergoes subsequent procedures, testing or genomic profiling, the results are automatically incorporated into this database.

Key Components

Software

- IBM WebSphere® Business Integration
- IBM DB2®
- IBM Data Discovery and Query Builder

Hardware

- IBM System p5™ 570

Services

- IBM Global Business Services
- T.J. Watson Research Labs

Time frame

- Design and prototype development: one year
- Full rollout: in progress

Why it matters

Using its recently built patient data infrastructure as a foundation, Sainte-Justine created a new process framework to automate the gathering, managing and updating of critical research information. By overlaying this with a powerful querying and analysis tool, Sainte-Justine gives its researchers real-time access to a vast and continually updated reservoir of clinical and genomic information, which will help speed childhood cancer research and improve patient outcomes.

In addition to automation and efficiency at the front end, Sainte-Justine's solution also provides a powerful analytical inquiry tool for researchers. By using the IBM Data Discovery and Query Builder (DDQB), Sainte-Justine's researchers are able to identify potential cohort members by specifying attributes at a very granular level virtually in real time, replacing a process that often required several months and substantial administrative resources. Even more powerful is DDQB's ability to analyze and identify correlations between elements of patients' clinical files and their genomic patterns. Formerly, such analysis required the manual inputting of data into a database and a database administrator to run complex routines. With the new solution, researchers themselves can use intuitive query language to see the relationship between genetic patterns and susceptibility to certain pediatric disorders. But this is just one dimension of the solution's capabilities.

Perhaps most important is the fact that the new solution gives Sainte-Justine's researchers the means to cross an important threshold in complex genomic analysis. Thus far, research has focused on "Mendelian" disorders, which examined the role of heredity in pediatric illnesses and birth defects. The new Holy Grail for pediatric research is to use genomic analysis to optimize the treatment of childhood diseases by understanding how a child's genetic makeup can impact their responsiveness to particular treatments, as well as their vulnerability to side effects. It's not uncommon for a child to receive a cocktail of half a dozen different drugs, with the impact of each component potentially affected by his or her genetic makeup. Understanding this complex relationship – a discipline known as pharmacogenomics – gives physicians a tool to maximize the effectiveness of childhood treatments while minimizing their side effects. Achieving this goal requires not only powerful analytical capability but also the ability to procure and validate a deep reservoir of patient information over time. Sainte-Justine's solution, by securely, efficiently and automatically performing this function, provides the hospital with a foundation for this next generation of pediatric research. To help build this foundation, Sainte-Justine's researchers worked with computational biologists from IBM T.J. Watson Research Labs.

Dr. Daniel Sinnett, head of the Oncogenetic Research at Sainte-Justine's Research Centre, expects the IBM solution to keep the hospital at the forefront of pediatric research, thereby increasing its ability to attract both funding and world-class research expertise. "Today our fundamental understanding of genetic susceptibility to disease is very limited, particularly in pediatrics," says Dr. Sinnett. "With IBM's assistance, we have vastly increased our ability to exploit the knowledge of the human genome in the way we understand and treat pediatric illnesses."

For more information

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