

MedMining

MedMining, a Geisinger Health System business: Commercializing custom, de-identified EHR-based data to promote healthcare research

Geisinger Health System

Geisinger Health System is an integrated health system based in Danville, Penn., that comprises a 700-plus multi-specialty physician practice, three hospitals, 40 community practice sites, a health plan, three research centers, and an internal venture group. One of Geisinger Ventures' portfolio companies, MedMining, provides customized, de-identified, electronic health record-based (EHR) data extracts to enable health economics and other biopharmaceutical research. The data is derived from numerous Geisinger Health System databases, most notably its EHR system.

Building a commercial model leveraging EHR data

Geisinger Health System was an early adopter when it implemented an EHR system in 1996. Through the years, Geisinger has invested more than \$100 million in its EHR system, clinical decision information system and other supporting resources to enable the integration of all disparate data sources, including those in departmental and stand-alone databases, as well as data in its EHR that is not readily reportable. A combination of Geisinger's financial investment, its nearly 100 percent adoption rate due to its physician-led staff model and its early implementation has resulted in MedMining's ability to extract 10-plus years of granular-level clinical, laboratory and economic data.

Early on, Geisinger's senior leaders realized the clinical value of leveraging its data and initiated several projects with the goal of deriving insight to patient care and providing clinical decision support for its patients. They also saw an opportunity to "grow the research pie nationally" by de-identifying and licensing its data, said Jim Peters, CEO of MedMining and Managing Partner, Geisinger Ventures. Geisinger leveraged the commercialization engine of its venture group to take it beyond a research project. Geisinger Ventures canvassed internal and external constituents and drew up a market-based business plan and a formal ROI analysis, and went well and above complying with HIPAA regulations to ensure that patient privacy was sacred.

Geisinger Ventures interviewed prospective customers to ensure that this type of anonymized data could, in fact, help promote research that otherwise wouldn't be possible. It also recognized the challenges and limitations of current research. In Randomized Controlled Trials (RCTs), qualified patients often have just one disease state as opposed to the complex web of co-morbidities that are often present in real-world patients. "We don't see observational studies or retrospective-based studies that MedMining enables as being RCT replacements, but we do see them as great validators or invalidators of specific RCT learnings," Peters said.

From data partner of last resort to great validator

One of MedMining's first clients was a company that had four important research questions that had gone unanswered for up to a year, as the company had been unsuccessful in identifying a data set that included the clinical detail across the care continuum required for the insight the customer sought. Unable to find retrospective data to support these studies, the company approached MedMining as a "data partner of last resort," Peters said. MedMining was able to provide granular data to support two of these four "orphaned" studies, and the company remains one of MedMining's largest, repeat customers. Another pharmaceutical company had been unable to collect data for its post-menopausal osteoporosis study, and as a result, its study had languished for some time. MedMining was able to extract data for fracture sites and bone mineral density scores, providing unique insight into strengths and weaknesses of different classes of therapies.

Had either company not gone to MedMining, the options would have been exhausting: change the research questions, study something else that is equally or nearly meaningful or create a prospective trial. The latter would require millions of dollars and other resources to recruit an appropriately consented cohort of patients and several years to build up de-identified, retrospective data, Peters pointed out.

To date, MedMining’s data partners include the top 10 pharmaceutical companies, as well as mid-scale and large biotech companies. Its data supports effectiveness research across the disease spectrum, including epilepsy, chronic obstructive pulmonary disease (COPD), hyperlipidemia, oncology, erosive esophagitis, gastroesophageal reflux disease (GERD) and post-menopausal osteoporosis.

MedMining leverages its “routine, open and collaborative” dialogue with the leaders of Geisinger’s three research centers—clinical trials, basic science and molecular biology lab, and clinical and applied outcomes—which has enabled the company to serve as one of Geisinger’s front ends for attracting work with nontraditional clients ranging from healthcare IT companies to genomics research firms.

Finally, a byproduct of MedMining’s business of providing a granular view of patient data is presenting Geisinger’s own physicians with a new, unique view of their patients’ data that can potentially provide insights to disease progression or therapeutic response that otherwise may have gone unnoticed, Peters said.

Best practices and lessons learned: Creating the gold standard

In establishing MedMining, Geisinger Ventures followed a number of protocols:

- Go far beyond HIPAA compliance as one’s mandate and develop a “belt, suspenders, Velcro and glue approach” to patient privacy and information security;
- Make the entire process transparent;
- Be extremely inclusive by casting a wide net within the organization and outside into the industry, including clinicians and prospective patients and customers, to garner opinions and counsel; and

- Create multiple levels of separation between the data and the end customer, including employing a formal Honest Broker System and inserting the Privacy Office as a process review checkpoint in the center of any data exchange to ensure the data is always completely de-identified and that neither MedMining nor its customers ever sees patient health information (PHI).

“Geisinger’s Honest Broker System is a construct that ensures there is a neutral, highly informed group of people—the ‘honest brokers’—committed to ensuring that privacy standards are always upheld,” Peters said. The honest brokers, who are required to be trained in HIPAA, PHI, research and other areas before serving, are not MedMining employees. They reside as a separate legal entity with their own separate reporting structure and submit their findings to Geisinger’s Privacy Office, which serves the entire health system, including MedMining.

Geisinger Ventures regularly seeks guidance from key informal advisors including representatives from its Internal Review Board, internal legal department and outside counsel, Information Security Office and Privacy Office. It chooses the Safe Harbor de-identification method permitted under HIPAA. A Geisinger entity that houses the Privacy Office—an entity that is separate and distinct from MedMining—has management responsibility over the Honest Broker. In addition, MedMining built automated SQL and Access-based database programs to make sure no PHI slips through. MedMining has never experienced a breach, but Peters noted that the company’s multi-layer process allows potential breaches to be addressed well before the data is ever released to the external research clients.

MedMining has experienced its share of challenges. Geisinger solved its technical challenge of having numerous department databases not tied to its EHR system and data in its EHR system that could not be readily reported on. On behalf of the integrated health

system, Geisinger Ventures championed the construction of an electronic data warehouse, or clinical decision information system, which integrates all the data. “Health systems shouldn’t underestimate the amount of investment it will take just to get at this data in a way that doesn’t compromise privacy, so that you can do this through an automated, de-identified mechanism,” Peters said.

Another challenge was the absence of an accepted industry standard for secondary use of data. “We had to ensure that whatever we were doing would be a gold standard for the industry,” Peters said. More and more health systems now have the ability to deliver broad and deep datasets and are interested in leveraging that data either with an offering of their own or as a data partner with MedMining, he said. “Others will come to us and learn what we did right and what we would have done differently,” he added.

While many health systems understand the value of leveraging their EHR data, misperception associated with licensing data is still an issue that must be handled with care, Peters said. Although it would have created a potentially greater revenue stream, MedMining decided against licensing its de-identified data to firms that wanted to use it for marketing. MedMining licenses its de-identified data strictly for health economics, research insights and safety outcomes, which supports Geisinger’s mission of providing greater insight into patient care globally. “The reality is we determined that it would be against our mission to take the path of least resistance and not start this business,” Peters said.

Growing the datasets to deliver more value

Going forward, MedMining wants to impact the industry on a much broader set of patients by integrating its data with those of other like-minded health-system peers who have three to four years of EHR history that crosses the care continuum or comes close to it, Peters said. The challenge is that few health systems today have the technology in place and the requisite historical data. That issue may be diminished as EHR adoption grows. Already, MedMining has been approached by a growing number of like-minded health systems with EHRs who would like to use MedMining as a vehicle for allowing their data to impact research as well. Instead of starting from scratch, these groups see the opportunity to leverage MedMining’s validated technology platform, entrenched market position and strong distribution channel relationships as a sensible, low-risk way to enter the market. “When we harness the power of our peers, we will bring to the industry a data offering that is even stronger than the compelling one we have today,” Peters said.

For Geisinger, it means removing its geographic and ethnic diversity constraints, given its regional clinical reach. The expanded data could positively impact research that examines, for example, the effect of therapies on certain ethnicities. At the end of the day, Peters said, “We’re willing to be the first to blaze the trail and at least begin to pave the way for others to do the same—be a pioneer in creating this whole body of data that otherwise hasn’t been available to researchers before.”