

# Improving Clinical Processes and Effectiveness of Care through Creation of a Disease-Specific Registry



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(per patient) physician time spent searching for data.



**2.2 minute reduction**  
(per patient) support staff time spent searching for data.



**300 percent increase**  
in investigator-initiated studies.

## PRODUCTS

- Health Catalyst® Data Operating System (DOS™)
- IDEA™

## EXECUTIVE SUMMARY

Multiple Sclerosis (MS) is a disease that affects the central nervous system of about 400,000 people in the United States. With no known cure, current treatment for MS is to slow disease progression, manage symptoms and maintain the patient's quality of life. Effective treatment of MS requires detailed patient information be readily available.

To better monitor disease progression and long-term patient outcomes, clinicians with OSF HealthCare Illinois Neurological Institute collaborated with researchers at the University of Illinois College of Medicine Peoria (UICOMP) to build a customized database, enabling self-service analytics. The success of the customized database suggests possible expansion may improve outcomes in other chronic or specialty care patient populations.

## FIGHTING MULTIPLE SCLEROSIS

Multiple Sclerosis (MS) is often a disabling disease that affects the central nervous system by disrupting the flow of information within the brain and between the brain and the body. An estimated 400,000 people in the United States have MS.<sup>1</sup>

OSF HealthCare Illinois Neurological Institute provides the care and treatment for more than 600 people with MS each year. OSF HealthCare is a health system owned and operated by The Sisters of the Third Order of St. Francis, including 11 acute care facilities, two colleges of nursing and a primary physician network consisting of more than 1,100 primary care and specialist physicians and advanced practice providers. The University of Illinois College of Medicine Peoria (UICOMP) is one of four campuses that make up one of the largest public medical schools in the U.S. In addition to medical student education and physician resident training, UICOMP provides direct patient care, basic science research and outcomes research services.

## TACKLING DISEASE PROGRESSION

To effectively monitor and treat MS, clinicians need access to various patient data. They include detailed information on medications—when started, responses to medication, when and if discontinued, why discontinued. Clinicians also require comprehensive information about physical mobility, including possible relapses. Because high variability exists among individual treatment, evaluation of the disease-modifying treatment over time is critical to symptom management and preventing disease progression.

Comprehensive patient information and treatment efficacy are incredibly important to monitoring and modifying treatment for people with MS. Many current EHR systems may prove a barrier to monitoring MS treatment and disease progression.



- Data outlining MS progression is contained in narrative note form. Obtaining data in this method is inefficient, may require investment in language processing algorithms, and is time-consuming.
- Not all data is equal. Data captured in an EHR may not be meaningful to monitoring treatment and disease progression. For example, the medication start date documented in the EHR may represent the date the medication is ordered, not when the patient first started the medication.
- Missing data elements. Important information such as the date of diagnosis, date of first onset of symptoms, and dates regarding treatments could not be easily obtained.
- Other important information required for insurance authorization forms or required to support clinical research were not easily obtained, requiring manual chart reviews and manual data entry.

## BETTER DATA FOR DEEPER INSIGHTS

OSF INI collaborated with the Center for Outcomes Research at UICOMP to develop an integrated MS “flowsheet registry” using the Health Catalyst® Data Operating System (DOS™) platform and broad suite of analytics applications, including the Instant Data Entry Application (IDEA™), part of the Health Catalyst Self-Service Analytics Suite. The methods used to create the registry are copyrighted by the University of Illinois.



MS history and progression is very individualized. Accessing pertinent information in a timely manner has improved the quality of clinician and patient interactions at clinic appointments.

**Kim Cooley, RN**  
**CRCC Research Nurse**  
**Jump Simulation & Education Center, a part OSF Innovation and a collaboration with the University of Illinois College of Medicine Peoria**

## Creating a chronic disease registry

Resource limitations made it difficult to customize the existing EHR, whereas IDEA could be easily customized to contain all of the needed clinical information. The OSF INI clinical team identified all of the clinical data elements that needed to be tracked to effectively care for MS patients. Working with the OSF Healthcare Analytics team and researchers from the Center for Outcomes Research at UICOMP, they developed a customized flowsheet or database using IDEA to collect the information that was not available in the analytics platform from other data sources. This application easily interfaces with the analytics platform, which allows OSF INI to combine data elements from the EHR and IDEA, enabling self-service analytics and comprehensive outcomes reporting.

In creating the MS flowsheet registry, OSF INI made sure to include comprehensive information about the patient's clinical presentation. As new treatments or the need for new data elements arise, IDEA is flexible enough to accommodate the addition of new findings. The clinicians, research team, and the OSF Healthcare Analytics team continue to collaborate to identify the important data findings that need to be captured within the flowsheet to create the greatest value for the providers, staff, and patients.

## One location for timely data

The MS flowsheet registry provides one, easy place to capture patient information, enabling a more effective review of a patient's disease treatment and progression over time. To ensure success, clinicians receive training on the registry prior to, during, and post-implementation. Using this engagement and support strategy, OSF INI attained complete adoption of the tool within nine months.

Each encounter with a patient triggers specific care team members at OSF INI to enter data into the MS flowsheet registry. For example, when a new or returning patient is expected to be seen in the clinic, an assistant reviews the EHR, adding the date MS was first confirmed into the registry. The nurse ensures the plan of care is entered/updated and checks that test results, including those from outside of OSF HealthCare are entered.

The data must be timely and accurate for the MS flowsheet to be effective. To support this, OSF INI created a designated research assistant position, funded through the Central Illinois MS Council, a not-for-profit volunteer organization dedicated to transforming health care for MS patients and their families in Central Illinois.



Capturing this much data on a patient is unreal. Not only is this transforming patient care but this opens our ability to conduct more meaningful research that will further our understanding of multiple sclerosis and future treatment efficacy.

**Carl Asche, PhD**  
**Professor and Director**  
**Center for Outcomes**  
**Research UICOMP**



Using a lean, agile approach, we leveraged available internal tools within the data warehouse to develop an inexpensive, efficient solution.

**Roopa Foulger**  
**Vice President of Data**  
**Delivery OSF Healthcare**

Once information is entered into the MS flowsheet registry, it is easy to review. Clinicians can review the date of initial diagnosis, date of initial symptoms, type of MS, comprehensive medication history including start and stop dates, relapse information, disease-modifying therapies, alternative therapies, motor assessments, MS severity scale assessments as well as all imaging and lab test dates and results applicable to MS treatment.

## RESULTS

Using IDEA as a customized MS flowsheet registry has given OSF INI the ability to visualize the entire clinical picture for each patient with MS over time. The MS registry has also increased the speed with which nurses and assistants can complete prior authorization activities, and has streamlined the pre-screening process used to identify potential participants for clinical trials. This has resulted in a:

- **20.9 minute reduction**, per patient, in the time the physician spends searching for data, a statistically significant reduction ( $p<.0001$ ).
- **2.2 minute reduction**, per patient, in the time support staff spend searching for data, a statistically significant reduction ( $p<.0001$ ).
- **300 percent increase** in investigator initiated studies, increasing OSF INI's contribution to the professional knowledge base.



Since first developing the MS flowsheet registry, OSF INI has conducted a retrospective study, evaluating the effectiveness of the database. This study has resulted in two publications and a poster presentation at an international conference. The first outlines the development of the flowsheet registry and the second describes the usefulness of the flowsheet registry to understand comorbidities associated with MS.<sup>2,3</sup> Results were displayed during a poster presentation at the 2017 Annual Consortium Multiple Sclerosis Center (CMSC) Conference on May 25, 2017 in New Orleans.<sup>4</sup>

## WHAT'S NEXT

Given the success of the MS flowsheet registry, OSF is evaluating the possible expansion of disease-specific registries integrated with the data in the analytics platform to further improve outcomes in other chronic patient populations. 

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## REFERENCES

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## ABOUT HEALTH CATALYST

Health Catalyst is a leading provider of data and analytics technology and services to healthcare organizations, committed to being the catalyst for massive, measurable, data-informed healthcare improvement. Our customers leverage our cloud-based data platform—powered by data from more than 100 million patient records, and encompassing trillions of facts—as well as our analytics software and professional services expertise to make data-informed decisions and realize measurable clinical, financial, and operational improvements. We envision a future in which all healthcare decisions are data informed.

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