



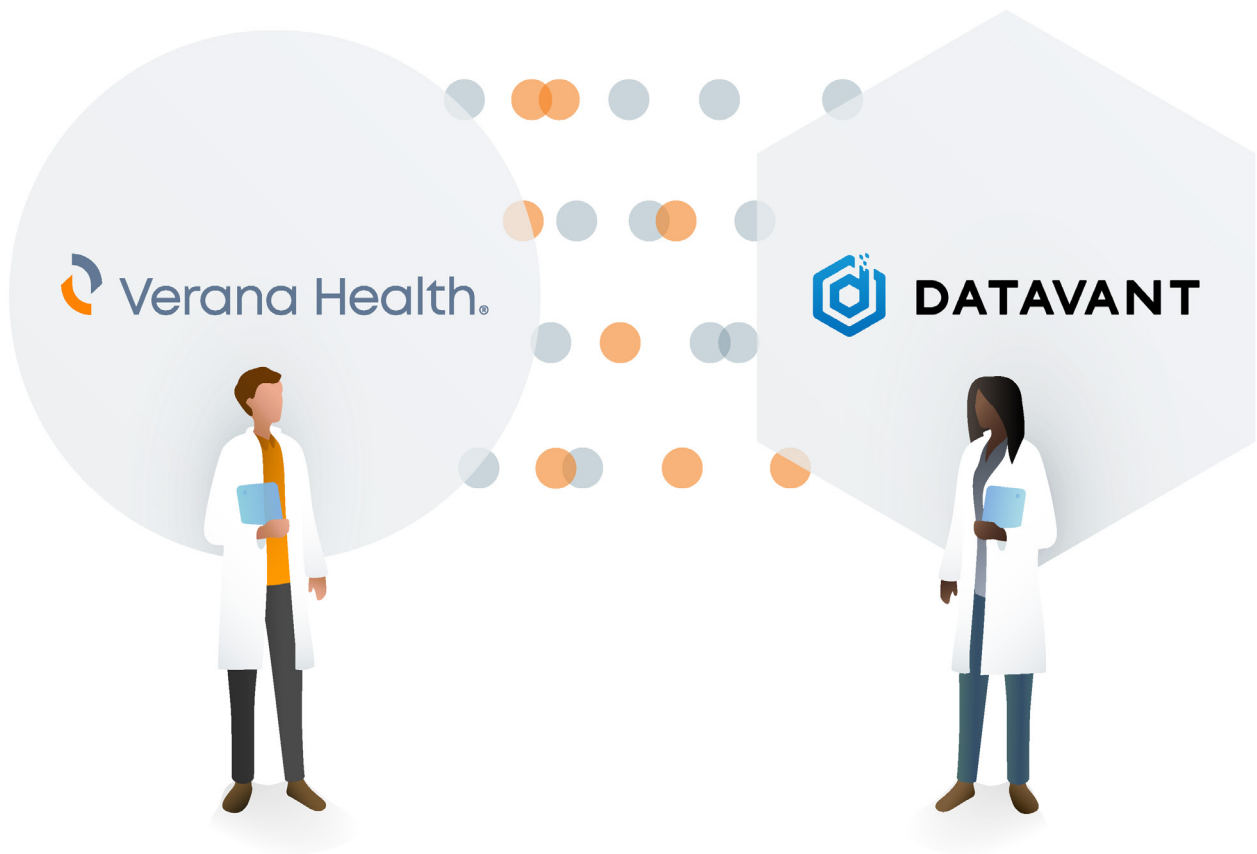
The Picture Comes Into Focus For Patients Suffering With Rare Eye Disease

Linking curated claims and registry data from electronic health records sheds light on full disease burden and healthcare utilization

Background

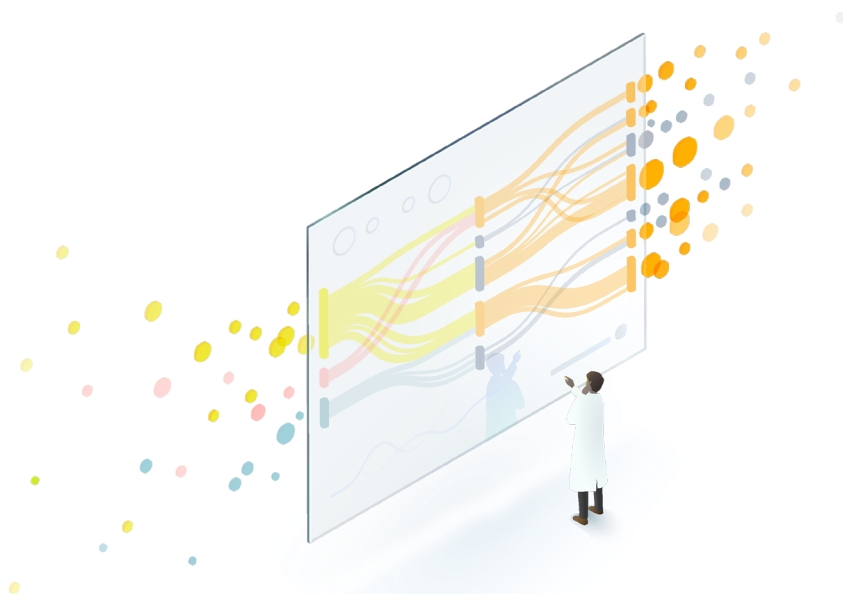
A sponsor developing a treatment for retinitis pigmentosa (RP), a rare degenerative hereditary disease, approached Verana Health® to access curated, de-identified data from the American Academy of Ophthalmology IRIS® Registry (Intelligent Research in Sight). The sponsor was interested in better understanding the complex disease burden that RP patients face, including clinical outcomes, comorbidities and total healthcare cost and resource utilization (HCRU).

The majority of retinitis pigmentosa patients suffer from diminished eyesight and eventually go blind. The clinical, social, and economic impacts of this disease are critical measures for a pharmaceutical sponsor in understanding the global burden of disease. Such data can help to contextualize the value of novel interventions, allowing pharmaceutical companies to quantify the potential benefit and cost offsets that can be achieved for therapies in development. HCRU data enables sponsors to assess incremental cost effectiveness and potential budget impact of these new therapies, core components of the health economics and outcomes research and payer value proposition.



Problem

Registry data helps to enhance the understanding of rare diseases. Sourcing clinical data from specialists who are treating these patients is the first step in understanding natural history. However, this model can provide a less than complete picture of patients, as data from care received outside of these specialized clinical settings may be missing. The risk is a misrepresentation of both depth and breadth – how the disease impacts patients holistically and across diverse backgrounds. Ophthalmologists are focused on treating eye disease, and while they do refer patients to specialists, they are not documenting the assessment and treatment plan for other specialties. Any diagnostic information from those referrals is not present in the record. Moreover, not all patients with rare disease are seen at care centers that contribute to a patient registry, especially if they are being treated in a community health setting. Thus, registry data alone may provide a limited view of rare disease patient populations.



By linking to a closed claims data source in a privacy-preserving manner, researchers were able to match patients across both data sets and analyze an enriched set of data with both EHR and claims data.

Solution

Curated, de-identified data from the IRIS Registry holds critical information about the clinical context and outcomes such as visual acuity. By linking to a closed claims data source in a privacy-preserving manner, researchers were able to match patients across both data sets and analyze an enriched set of data with both EHR and claims data. The joint dataset captured other systemic comorbidities managed outside of the ophthalmology setting and other healthcare interactions relevant for measuring the global burden of disease.

Methods

The IRIS Registry contains 9 years of longitudinal data from more than 75 million unique patients and more than 16,000 ophthalmologists and other eye care providers. The registry has a technology foundation managed by Verana Health's VeraQ® population health data engine. For this project, a large closed claims data source was licensed to provide additional information.

Both sources used Datavant's tokenization technology to strip out patient-identifying information (PII) and replace it with an irreversible hash called a token. These "tokens" were then used to identify matching patients between the two data sets to create a combined data set with attributes from both registry data and claims data. This combined data set went through expert determination, which is a HIPAA compliant way to ascertain de-identification. This process resulted in a certification that the combined data set remains HIPAA compliant and that the risk of re-identification remains low.

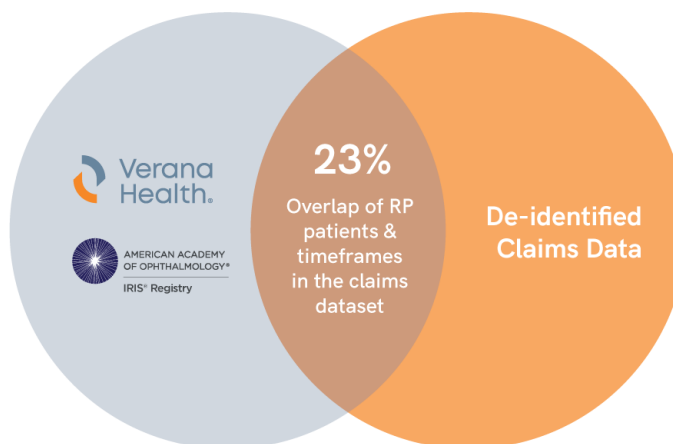
These "tokens" were then used to identify matching patients between the two data sets to create a combined data set with attributes from both registry data and claims data.

A cohort of patients with RP was identified by looking for at least two encounters with relevant diagnosis codes. With the linked data sets, researchers created a comparator cohort that matched on age, sex, and Charlson Comorbidity Index so that the de-identified patients with RP could be compared to a more general population when assessing cost of care. The burden of disease was also evaluated by analyzing the number of visits and procedures performed.

The overlap of patients in the cohort of interest was ~23% with the claims data set.

Patient Cohort Criteria for Retinitis Pigmentosa Real-world Data Study

- Two distinct documented diagnosis of hereditary retinal dystrophies
- Complete demographics (age 1 - 120 and no missing sex)
- Claims encounter between index and censor date



*Connectivity powered by Datavant



Results

Tokenizing the specialty registry that had rich, clinical data curated by Verana Health enabled this analysis to happen quickly and efficiently. The combination of claims data using Datavant as a neutral, trusted technology partner, helped answer questions critical for the sponsor related to patient experience, disease burden, and health care utilization.

In 2023, it's expected that the need for linkages between various types of data, including EHR, claims, diagnostic imaging, genomics and clinical trial data, will grow. In order to link de-identified data, identifiable elements are tokenized and encrypted to prevent reidentification. Use of these tokens enables linking between de-identified datasets while safeguarding protected health information.

By linking these rich data sets, Verana Health's research-ready, fit-for-purpose data modules (Qdata®) can help inform real-world evidence and unlock quality research insights for life sciences organizations.

Tokenizing the specialty registry that had rich, clinical data curated by Verana Health enabled this analysis to happen quickly and efficiently.

About Verana Health

Verana Health® is a digital health company elevating quality in real-world data. Verana Health operates an exclusive real-world data network of more than 20,000 healthcare providers (HCPs) and about 90 million de-identified patients, stemming from its strategic data partnerships with the American Academy of Ophthalmology, American Academy of Neurology, and American Urological Association. Using its clinician-informed and artificial intelligence-enhanced VeraQ® population health data engine, Verana Health transforms structured and unstructured healthcare data into curated, quality data modules, Qdata®. Verana Health's Qdata helps power analytics solutions and software-as-a-service products for real-world evidence generation, clinical trials enablement, HCP quality reporting, and medical registry data management. Verana Health's quality data and insights help drive progress in medicine to enhance the quality of care and quality of life for patients. For more information, visit www.veranahealth.com.

About Datavant

Datavant's mission is to connect the world's health data to improve patient outcomes. Datavant works to reduce the friction of data sharing across the healthcare industry by building technology that protects the privacy of patients while supporting the linkage of patient health records across datasets. Learn more about Datavant at www.datavant.com.