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Datavant Life Sciences Case Study

Finding Rare Disease Patients

Client Situation

Hereditary ATTR amyloidosis is a rare disease that affects 50,000 patients world-wide, shortening patient life expectancy to between five and thirteen years.[1] Finding patients is difficult because the disease symptoms are heterogenous – it affects CNS, cardiovascular, renal and gastrointestinal systems. Patients may go years seeing a variety of specialists before being correctly diagnosed.

A pharma client with a therapy for the disease sought to accelerate identification of patients. The client had a sponsored genetic test to confirm diagnosis of hATTR amyloidosis. They partnered with an Advanced Analytics company to develop a model to identify patients likely to have hATTR amyloidosis so they could be administered the genetic test. To train and validate this model, the client needed a cohort of patients who had already taken the test, with their test results linked to their medical and pharmacy claims.

Once the predictive model was validated, the client applied the model to claims sources to identify physicians seeing potential hATTR amyloidosis patients. These physicians were targeted for education so their patients could be administered the genetic test to confirm diagnosis and placed on therapy.

How Datavant Helped

Datavant provided the matching and linking solution to connect data from patients who took the genetic test to claims data that the company used to develop and validate its predictive model.

The model was deployed in a Datavant partner's claims dataset to identify physicians seeing potential hATTR amyloidosis patients.

Results

The test was administered to patients identified through this approach resulting in more than 60 new hATTR amyloidosis patients.