Clinakos™

Also Non-Rare!

CASE STUDY

PATIENT JOURNEYS AND INSIGHTS FOR ONCOLOGY AND RARE DISEASES

Via Patient-Consented, Linked Claims, EMR, Lab, Rx & Dx Records

ADVANTAGES:

Linked patient records across 90% EMRs, 99% Pharmacies, 90% Labs (coverage of over 90% of the US population)

Over 100,000 signed-up Oncology and Rare Disease patients and caregivers across 563 indications

Qualitative and quantitative research with linked medical records

Project delivery within weeks

The Challenge

Creating robust patient journeys for rare disease patients is challenging. Rare disease patients are very difficult to find. Their data is often lacking in syndicated or aggregated data sets due to the rarity of the conditions. Even when the patients can be found, it is difficult to ensure that their relevant medical data is properly captured. Current qualitative and quantitative research techniques produce unsatisfactory results. Patients often are not aware of or can't remember their current and past medical details (like their medications, treatments, exact diagnoses).

With all these difficulties in mind, we picked an extremely rare oncology indication with an aim of understanding patient journeys for this population.
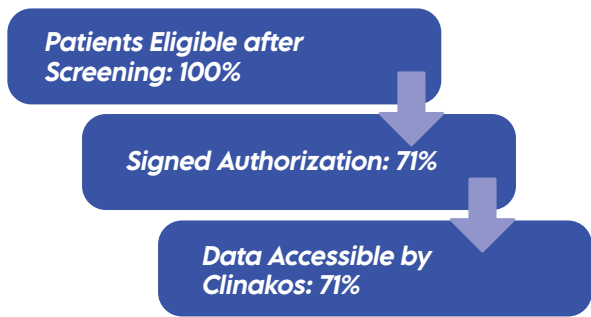
Our Solution

Clinakos partnered with Rare Patient Voice (RPV) to facilitate insights for this rare oncology indication. RPV has signed up over 100,000 patients to participate in research across 563 diseases. This access created a unique capability to obtain a cohort of patients who were excited about contributing to research.
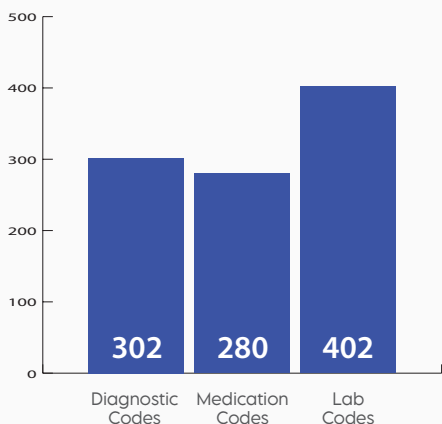
Armed with patient authorizations, Clinakos was able to leverage their integrations across the healthcare ecosystem (which includes all major EMRs, Pharmacies, Labs, Devices and Socio-Economic sources) to gather all of the relevant data on these patients, creating a digital twin for each patient. These were used to create the patient journeys on these rare oncology patients.

CASE STUDY

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Results

Of the rare oncology patients who showed initial interest, 71% authorized us to gather their medical data. Of the recruited 71%, we were able to gather data on all of the patients. We found electronic documents for these patients ranging from 2008 to 2021. The patients averaged 127 different charts per patient often spanning multiple healthcare systems, physicians, payers, labs, pharmacies and other institutions. A breakdown of the data collected on these patients follows below.

Patients Eligible after Screening: 100%

Signed Authorization: 71%

Data Accessible by Clinakos: 71%

UNIQUE CODES

Bar chart values:
- Diagnostic Codes: 302
- Medication Codes: 280
- Lab Codes: 402

DIAGNOSES:

Patients averaged 39.2 different diagnoses across 302 different diagnosis codes in their medical histories. Using this data, we were able to confirm if the patients had the key diagnosis in question for each of the patients. We found diagnosis on 100% of the consented patients and excluded the 7% of patients who did not have the diagnosis in question for the study.

MEDICATIONS:

Patients averaged 39 different medications across 280 different medication codes in their history. On average, patients were taking 21 different medications at the time of the project.

LABS:

There was an average of 192 lab reports per patient. These reports contained 402 different lab test codes and results. Examples of tests included CD19, CD4, absolute lymphocyte count, albumin/creatinine ratio, beta2M, bilirubin total, CD3 absolute count, EGFR, immature granulocytes, hepatitis c antibody, LDH, phosphorus, prothrombin time, triglycerides, and white blood cell count.

EMR NOTES:

The information collected also included EMR notes which contained many useful insights. Some example insights include:

- Reason initial therapy was modified was due to neuropathy on the second round of chemotherapy treatment
- Final round of treatment for a patient withheld due to non-myeloid toxicities
- Symptom descriptions
- Untreated conditions
- Patient non-medical activities

SAMPLE EMR NOTE:

He went back for biopsy of the splenic mass on XX/XX/201X that showed germinal center lymphoma. The cells were CD10 positive and the cells were also positive for Pax5, Bcl-2, and Bcl-6, negative for CD3, CD30, myc and MUM1, and cyclin D1. The Ki-67 was more than 80%. The patient was started on XXX chemotherapy. He had two full cycles of XXX. The third cycle, he had no XX because of mild neuropathy.

Detailed data on medications, labs, diagnoses and EMR notes provided a comprehensive picture into the patient journeys of this rare oncology population. Clinakos and RPV are committed to applying these unique capabilities for research and improving the quality of life of patients.

To learn more, contact us at **sales@clinakos.com** or **ContactUs@RarePatientVoice.com**