

The HCP Rare Disease Study

More than half (51%) of U.S. physicians report seeing patients diagnosed with a rare disease.* Yet limited disease-specific and treatment data can delay diagnosis and care. To help close this gap, **M3 MI is proud to introduce the HCP Rare Disease Study, one of the industry’s first and most comprehensive syndicated research efforts designed to help healthcare marketers effectively reach and inform these HCPs.** The study will be available in Q3 2026.

HCP Rare Disease Study by the numbers:	7 therapeutic area clusters covering 90+ conditions		
	20+	Valued info sources for rare disease research	
	15+	Medical / surgical specialties	
	10+	Barriers encountered in diagnosing patients	
		10+	Content formats likely to use in finding condition info

With this study healthcare marketers will be uniquely positioned to:

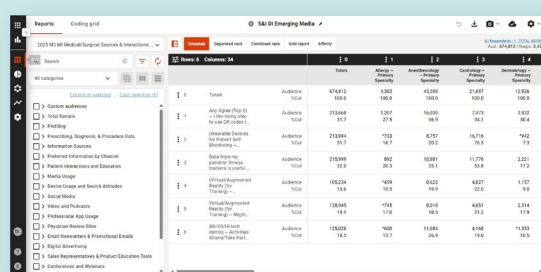
Create Precision HCP Segments
Go beyond demographics by identifying HCPs based on how they practice, influence peers, and the specific clinical evidence that drives prescribing decisions. This allows more granular, **behavior-driven segmentation** that mirrors the reality of rare disease specialists.

Optimize Journey-Based Engagement
Map diagnosis and treatment touchpoints to align messaging from initial awareness through ongoing management. **Create cohesive HCP and patient education** that supports continuity of care and addresses the unique friction points of a rare disease diagnosis.

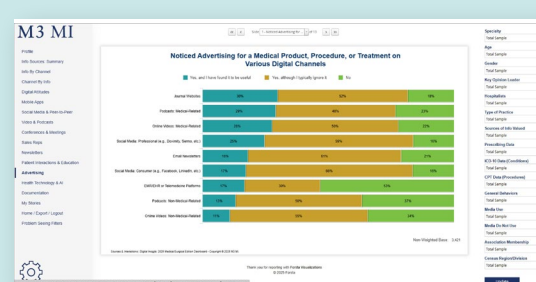
Accelerate Diagnosis & Treatment Initiation
Identify diagnostic barriers and misdiagnosis patterns to deliver earlier education, awareness, and decision-support resources in the digital channels HCPs value when researching rare or hard-to-diagnose conditions.

Connect HCP and DTC data for meaningful impact
The most impactful healthcare strategies happen where HCP and patient insights meet. Our **2026 Rare Disease Patient & Caregiver Study** is designed to synchronize these two worlds – pinpointing the moments where patient advocacy and HCP clinical action converge, ensuring your strategy is unified across the communication ecosystem.

Flexible data access options:



Telmar Platform
Explore crosstab audience analysis tool



The Dashboard
An interactive data visualization tool for quick views and exporting to PowerPoint

To ensure reliable and reportable data, conditions will be grouped into various therapeutic area clusters based on the nature of the disease:

Blood Disorders Group

- Beta Thalassemia / Hemoglobinopathy
- Hemophilia A or B
- Immune Thrombocytopenia
- Paroxysmal Nocturnal Hemoglobinuria (PNH)
- Primary Systemic Amyloidosis
- Sickle Cell Disease
- Thrombotic Thrombocytopenic Purpura

Cancer: Blood and Bone Marrow Group

- Acute Lymphoblastic Leukemia (ALL)
- Acute Myeloid Leukemia (AML)
- B-cell Precursor Acute Lymphoblastic Leukemia
- Chronic Lymphocytic Leukemia (CLL)
- Chronic Myeloid Leukemia (CML)
- Diffuse Large B-Cell Lymphoma (DLBCL)
- Hodgkin's Lymphoma (HL)
- Indolent B-Cell Non-Hodgkin Lymphoma (NHL)
- Multiple Myeloma
- Myelodysplastic Syndromes (MDS)
- Myelofibrosis

Cancer: Solid Tumor Group

- Brain and Central Nervous System (CNS) Tumors
- Desmoid Tumors / Aggressive Neurofibromatosis
- Endometrial Cancer
- Esophageal Cancer
- Gastric (Stomach) Cancer
- Gastroenteropancreatic Neuroendocrine Tumors
- Glioblastoma
- Kaposi Sarcoma
- Malignant Pleural Mesothelioma (MPM)
- Merkel Cell Carcinoma (MCC)
- Pediatric Low-Grade Glioma (pLGG)
- Other Pediatric Cancer
- Primary Peritoneal Cancer
- Renal Cell Carcinoma
- Small Cell Lung Cancer (SCLC)
- TNBC (Triple-Negative Breast Cancer)
- Urothelial Carcinoma

Cardiac Conditions Group

- Dilated Cardiomyopathy
- Hypertrophic Cardiomyopathy
- Pulmonary Arterial Hypertension
- Transthyretin Amyloid Cardiomyopathy (ATTR-CM)
- Other Cardiomyopathy

Growth Disorders Group

- Achondroplasia
- Acromegaly
- Cystic Fibrosis
- Growth Hormone Deficiency
- Prader-Willi Syndrome (PWS)

Immune/Autoimmune Group

- ANCA Associated Vasculitis
- Axial Spondyloarthritis (axSpA)
- Bullous Pemphigoid (BP)
- Chronic Granulomatous Disease (CGD)
- Chronic Spontaneous Urticaria (CSU)
- Crohn's Perianal Fistulas (CPF)
- Eosinophilic Esophagitis
- Giant-Cell Arteritis
- Graves Ophthalmopathy
- Hereditary Angioedema (HAE)
- IgA Nephropathy (IgAN) or Focal Segmental Glomerulosclerosis (FSGS)
- Interstitial Lung Disease/Idiopathic Pulmonary Fibrosis
- Primary Biliary Cholangitis / Cirrhosis
- Primary Immunodeficiency (PID)
- Prurigo Nodularis
- Systemic Lupus Erythematosus (SLE)

Infectious Diseases Group

- Meningitis B

Metabolic Group

- Duchenne Muscular Dystrophy
- General Kidney / Chronic Kidney Disease
- Hereditary Transthyretin-Mediated Amyloidosis with Polyneuropathy (ATTRv-PN)
- Hypoparathyroidism
- Hypophosphatasia
- NASH/MASH/MASLD
- Nephropathic Cystinosis
- Niemann-Pick Disease Type C
- Ornithine Transcarbamylase (OTC) Deficiency
- Osteogenesis Imperfecta (OI)
- Primary Hyperoxaluria Type 1 (PH1)
- Primary Mitochondrial Myopathy
- Thymidine Kinase 2 Deficiency (TK2D)
- Transthyretin Amyloidosis (ATTR)
- Wilson Disease

Neurological Group

- Bipolar (BD-1 & BD-2)
- Chronic Inflammatory Demyelinating Polyneuropathy (CIDP)
- Dravet Syndrome
- Friedreich's Ataxia (FA)
- Huntington's Disease
- Idiopathic Hypersomnia
- Lambert-Eaton Myasthenic Syndrome (LEMS)
- Lennox-Gastaut Syndrome
- Metachromatic Leukodystrophy (MLD)
- Multiple Sclerosis
- Myasthenia Gravis
- Narcolepsy
- Neuromyelitis Optica Spectrum Disorder (NMOSD)
- Neurotrophic Keratitis
- Parkinson's Disease
- Spinal Muscular Atrophy (SMA)

A complete view of HCPs treating patients with rare diseases, including the **sources they value and information they need across the diagnosis and treatment journey**

Robust Profiling Data

Demographics

Gender, age, ethnicity

Professional view

Primary medical specialty and subspecialty, location and type of primary practice, years in practice, work within a Center of Excellence or Specialty Care Center, number of patients seen, percentage of patients with rare conditions, professional activities, work-related digital activities

Level of Influence

Key opinion leader (KOL), digital opinion leader (DOL), consulted by other physicians for opinions regarding treatment

Prescribing behavior

Number of Rx written, adoption of new treatments/devices/procedures, factors influencing decisions

Engagement Activities With Rare Patients

Make an initial diagnosis, referred patient to a specialist for diagnosis, managed the long-term care of the patient, treated with an FDA-approved medication, treated symptoms with an off-label or palliative treatment, enrolled or participated in a clinical trial for a rare disease, provided care coordination with other specialists

Professional Use of AI

Types of AI activities used in practice, primary concerns regarding AI in your practice, extent of patient use of AI-driven tools influencing their expectations about potential treatments or cures, attitudes towards: AI improving diagnostic accuracy, AI making it easier to find info on rare diseases, patient use of AI in fostering more productive clinical conversations, and has diagnostic AI made it easier to determine tests for diagnosis

Patient Interaction

How HCPs and patients make medical decisions together, influence of cost on choice of therapy, frequency patients bring health info found online/AI to appointments, types of info patients lack or need vs. what is currently available during treatment journey stages

Diagnosis Journey

How rare or hard-to-diagnose condition patients find HCP, length of time to confirm diagnosis, percentage of patients arriving with previous misdiagnosis, types of barriers encountered in diagnosing patients with rare or hard-to-diagnose condition

Treatment Journey

Most frequent challenges in initiating/changing treatments, usefulness of various aids or patient educational resources in treating/diagnosing, most influential sources of evidence in decision to prescribe off-label in the absence of FDA-approved therapies for a condition

Information Needs

Sources valued in gathering info about rare or hard-to-diagnose conditions, sources relied on for treatment guidance, content formats likely to use for info on hard-to-diagnose conditions

Social Media

Frequency used to gather diagnostic advice for difficult cases, impact a Subject Matter Expert (SME) on social media has on clinical decisions