

The Rare Disease Patient and Caregiver Study

An estimated 25–30 million Americans live with a rare disease*, often navigating long, complex healthcare journeys with limited disease-specific information. To help close this gap, **M3 MI is proud to introduce our new Rare Disease Patient and Caregiver Study, one of the industry’s first and most comprehensive syndicated research efforts focused on this often-overlooked population.** The study will be available in Q3 2026.

<p>Rare Disease Patient and Caregiver Study by the numbers:</p>	<p>7 therapeutic area clusters covering 90+ conditions</p>	
	<p>90+ Health attitudes, behaviors and actions taken</p>	<p>15+ Information needs profiled at 5 patient journey stages</p>
	<p>10+ Information sources with details on trustworthiness and reasons to use</p>	<p>20 Barriers to treatment</p>

With this study healthcare marketers will be uniquely positioned to:

Build data-driven patient and caregiver personas

Leverage specialized therapeutic area clusters, grouped by condition type, treatments, or physiological impact to build stable, actionable personas. Utilize detailed profiling and SDOH to understand the attitudes and life stages that drive rare disease decisions.

Activate effective communication and engagement

Identify health information needs and media channel consumption with a focus on social media, influencers, AI, video and other digital media to pinpoint engagement that will have impact.

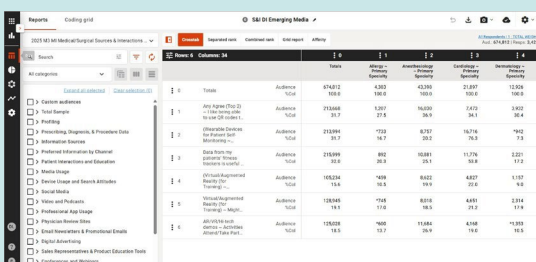
Map the rare disease care journey

Access aggregated data sets to learn about the diagnosis and treatment stages of their journey: pain points in diagnosis, barriers to treatment, the role of caregivers in decision-making, and much more.

Connect HCP and DTC data for meaningful impact

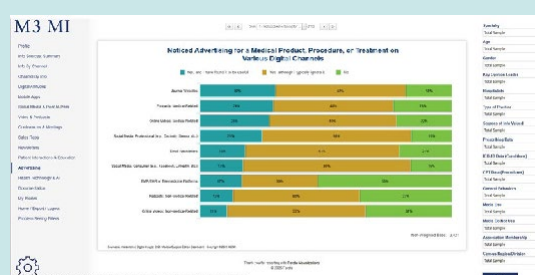
The intersection of HCP and DTC strategies represents one of healthcare marketing’s greatest opportunities. That insight shaped the design of our **new HCP Rare Disease Study** (releasing in 2026), built to pinpoint barriers and engagement opportunities along the treatment journey that drive meaningful impact across patients, caregivers, and HCPs.

Flexible data access options:



Telmar Platform

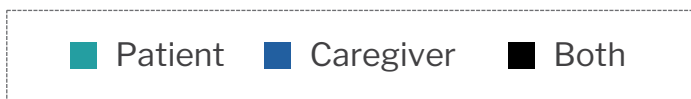
Explore crosstab audience analysis tool



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

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

Cancer: Blood and Bone Marrow Group

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

Cancer: Solid Tumor Group

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

Cardiac Conditions Group

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

Growth Disorders Group

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

Immune/Autoimmune Group

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

Infectious Diseases Group

- Patient Meningitis B

Metabolic Group

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

Neurological Group

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

A complete view of rare disease patient and caregiver **information needs across the healthcare journey**

Profiling

Gender, age, ethnicity, languages spoken at home, employment, annual HH income, education, relationship status, parent, # of children in HH, health condition group patient or caregiver

Caregiver Specific Profiling

Relationship to the person they care for, age of loved one with the condition, whether they live with the loved one, what activities they handle on the loved one's behalf, how involved they are in medical/treatment decision discussions

Diagnosis Journey

Time from first symptoms to diagnosis, current stage in the patient journey, has patient ever received a wrong diagnosis, timing to correct diagnosis, is patient currently being treated, time from diagnosis to first treatment, how the diagnosing doctor was found, diagnosing doctor's specialty, types of tests required before diagnosis, specialty of the doctor primarily managing the condition

Treatment Journey

Current treatments using, how treatment decisions are made, where the patient receives care, has the patient stopped/changed treatment and why, treatments impact on daily life, attitudes about current treatment, difficulties experienced accessing treatment

Treatment Cost and Impact

Type of insurance patient has, use of specific resources/ programs to help pay for prescription, types of actions/ sacrifices done to help pay for treatment, how much concerns about treatment cost affect their stress level

Social Determinants of Health

Types of challenges faced related to their own health or condition

Health Information Needs

At what points they lacked enough information to make a confident decision: before diagnosis, at the time of diagnosis when deciding on treatment, when managing daily life, when symptoms changed or treatment stopped working

Which health-related activities they've done online, sources used for those activities, trust of each source for condition info, for trustworthy sources how they used

What percent of their internet use is spent consuming health/medical information.

Health Attitudes

Others come to them for healthcare/medication advice, feeling anxious about how the condition affects/will affect them, feeling they have control over health and quality of life, relationship with the doctor treating the condition

Physical and Mental Health Status

Current health status, severity of the symptoms, impact condition has on daily activities, goals most important to you in treating your condition

Home Assistance and Caregiving

Has respondent received caregiving assistance, who primarily assists, does the primary caregiver live with them, involvement of the caregiver with medical choices/treatment discussions

Caregiver Specific Questions

Most important treatment goals for loved one, challenges faced, attitudes on emotional, social, and practical impacts of caregiving, including both the challenges and potential positive aspects of the experience

In-depth **media preferences and behaviors** tied to health conditions and treatments

Time Spent With Media

Hours per weekday or weekend spent watching TV

Hours per day spent:

- Listening to radio, podcasts, or streaming music
- Using the internet
- On social media
- Watching online videos

Types of audio formats listened to, methods used to watch TV, which social media platforms used, have they used any patient community websites

Healthcare Advertising

Where seen/heard any healthcare ads, actions taken because of noticing healthcare ads, attitudes towards healthcare advertising

Online Health Attitudes

Sharing health data online, referring other to helpful websites, conduct research online prior to appointment, trust medial info others share on social media, info online that influences treatment, online communities make me feel less alone, seeing condition information online makes me feel overwhelmed, confidence in ability to distinguish between quality medical evidence and unverified claims

Use of AI for Health

Specific AI tools used for health purposes, types of AI tools used to manage health, what features are important when using an AI for condition/treatment info, attitudes towards AI-generated health info, does AI summaries in search results meet the patient's needs, do they trust AI recommendations as much as advice from an HCP, is AI helpful in helping manage the condition