



IPSOS' CENTER OF EXPERTISE FOR RARE DISEASES

Six Stories of Success



SIX STORIES OF SUCCESS

Ipsos' Global Center of Expertise for Rare Diseases is responsible for integrating, innovating and internally cascading Ipsos' expertise in rare diseases research.

Our specialists provide bespoke research solutions, real-world evidence and advisory services to our clients – responding to their every business need with the unique combination of our knowledge, resources & connections.

THE RARE DISEASES CoE: OUR CAPABILITIES

● Qualitative Research Solutions

- » Market landscaping
- » KOL research
- » Patient journey research
- » Ethnography and in-context research
- » Communication & disease education material development

● Quantitative Research Solutions

- » Market sizing
- » Treatment and referral mapping
- » Patient journey research
- » Patient chart audits
- » Awareness and usage tracking
- » Message recall testing

● Syndicated Real-World Evidence

Ipsos' Global Therapy Monitors provide a 360° real-world view of patient treatment in c.40 diseases, including...


- » Hemophilia
- » Sickle Cell Disease (SCD)
- » Pulmonary Arterial Hypertension (PAH)
- » Transthyretin Amyloid Cardiomyopathy (ATTR-CM)
- » Transthyretin amyloidosis with polyneuropathy (ATTR-PN)

● Pricing & Market Access

- » Over 50 market access projects in rare diseases

● Creative Recruitment & Respondent Access

- » Multiple recruitment partners and experience in connecting with the right respondents through advocacy groups, patient forums, physician referrals, etc.



THE CENTER OF EXPERTISE HAS
BROAD EXPERIENCE ACROSS A
VARIETY OF RARE DISEASES – JUST
SOME OF WHICH INCLUDE...

SIX STORIES OF SUCCESS: RARE DISEASES CENTER OF EXPERTISE



CASE STUDY:

PAYER VALUE MESSAGES FOR AN ASSET IN A RARE BLEEDING DISORDER

Situation

Our client was preparing the global launch of a fibrinogen concentrate and needed to understand how to best present the product's value story based on payer archetypes. This was all the more pertinent as each launch country had heterogeneous clinical practices and competitive environments, and the brand was applicable to more than one indication.

Approach

Ipsos completed a full review of all available materials to ensure an optimum understanding of the therapy area and competitive environment. Collaborating with the client helped refine value messages and link them to relevant payer archetypes and country clusters.

Outcome

An understanding of different payer expectations and local commercial environments led to tailored value messages applicable to the launch markets and adaptable to future markets.



CASE STUDY:

GLOBAL KOL MAPPING IN WILSON'S DISEASE



Situation

In order to effectively organize future KOL and educational events for Wilson's disease, our client required the identification of said KOLs, clinicians and scientists prominent in this disease area, and a library of currently listed past and future events.

Approach

Accessing in-house databases, publicly available information and working in several languages, Ipsos researched speakers/ attendees at past and future Wilson's Disease events, published authors, and clinicians leading efforts with patient advocacy groups.

Outcome

We compiled a comprehensive and bespoke database for our client, containing details of KOLs from over 40 countries. Subcategories within the database allowed the client to review key demographic data, as well as publications, conference attendance and notification of future events; this aided the company in future event planning and KOL coordination.

CASE STUDY:

PATIENT & HCP SEGMENTATION TO SUPPORT A RECENTLY LAUNCHED BRAND

Situation

In order to optimize the management of its Rare Pulmonary Disease brand, our client sought a comprehensive review of its current methods for targeting physician & patient audiences.

Approach

Interviews across more than 400 Rare Pulmonary Disease patients were conducted; in parallel, we mirrored the questionnaire and ran equivalent research amongst physicians. This gave rise to insight that allowed the creation of very new, and improved, targeting and communication strategies for both audience types.

Outcome

In conjunction with creative agencies, our client prepared new Rare Pulmonary Disease patient communication material, brand stories to address specific patient concerns and redesigned brand websites. Specific messages were created to inform physicians of optimal brand usage in the treatment pathway. All this was possible based on our insights and recommendations.



CASE STUDY:

EXPLORING THE PATIENT JOURNEY OF A SPECIFIC GENETIC CONDITION

Situation

With regards to a specific genetic condition, our client required a detailed understanding of the patient journey within the Hispanic community – in order to uncover barriers to optimal quality of life.

Approach

Leveraging the Ipsos Hispanic Center of Excellence, a multi-step and culturally relevant approach was implemented, using webcam TDIs across HCPs, patients and caregivers.

Outcome

Uncovering unmet needs in relation to patient information, education and local-level support led to the development of Spanish-language materials, seminars and conferences to promote awareness and dialogue within this community.



CASE STUDY:

ILLUMINATING UNMET NEEDS TO FOSTER A PATIENT SUPPORT INITIATIVE

Situation

Prior to bringing a new product to market for a rare disease, our client needed to understand the unique patient journey to inform the development of a patient support initiative.

Approach

Due to the rarity of the disease and prognosis, efforts were tailored for recruitment; patients and caregivers were recruited for IDI webcam interviews with the help of advocacy groups, social media support platforms and KOLs.

Outcome

Ipsos illuminated the patient experience to the client, identifying a key need for understandable information about the disease for patients and caregivers. Creative concepts for the patient support initiative were crafted; these will help connect patients and caregivers with other families on a similar journey, and with the resources they need to better understand their condition.

CASE STUDY:

BUILDING A VALUE PROPOSITION FOR A FIRST RARE DISEASE TREATMENT

Situation

Our client was developing a first and only treatment for a rare hepatic disease; they needed a solid understanding of the market and characterization of patients to appropriately assess how their asset would be received.

Approach

Ipsos adopted a 3-pronged approach to best inform our client's strategy for building a value proposition in this market:

- » Primary research to understand patients' experience with the disease
- » Primary research to understand the treatment flow / buying process
- » Patient chart capture to understand the disease burden and the real-world treatment landscape

Outcome

A stronger understanding of the market, patient types and management approaches helped determine where the brand would fit. In addition, with support from the Ipsos HEOR team, the client published insights from the patient chart capture to demonstrate an unmet need for treatment in this rare disease. Strategies targeting both physicians and patients are currently being created by the client as a result.



CONNECT WITH US:

Lynda Levy

Lynda.Levy@ipsos.com

+1 609 731 1688



ABOUT THE IPSOS HEALTHCARE SERVICE LINE

We are a global insight, analytics and advisory partner to the healthcare sector. Our multi-disciplinary teams deliver integrated services and proprietary real-world evidence across the product lifecycle. This enables our clients to act with clarity, certainty and speed.



www.ipsos.com