

Rare diseases – of which **6,000+**
have been identified to date*
– are heterogeneous and often
under- or mis-diagnosed.

Faced with unique challenges,
patients with rare diseases seek
equitable access to diagnosis,
treatment, health, social care
and opportunity...

*Source: 'Estimating cumulative point prevalence of rare diseases',
European Journal of Human Genetics (nature.com)



Despite a lack of understanding of rare diseases, there appears to be strong public interest...

An Ipsos survey in Ireland found that only **13%** of people aware of the term 'rare disease' could correctly identify a condition.

However, **69%** expressed an interest in learning more about it.

Source: Ipsos survey conducted via telephone among nationally representative sample of 1,019 adults in Ireland aged 15+ from June 1 - 14, 2023



Patients with rare diseases face significant challenges with delayed diagnoses...

An Ipsos survey in Canada found that patients saw an average of **5.9** different healthcare professionals, received an average of **3.2** wrong diagnoses, and waited an average **3.7** years for an accurate diagnosis.

Source: Ipsos survey conducted online among 528 Canadian caregivers and patients living with rare diseases from October 26 to November 28, 2022



Patients with rare diseases and their caregivers use online channels to connect & share experiences...

- Around **40%** of US rare disease patients/caregivers sourced information for a diagnosis from a patient community.
- Around **30%** sourced information from social media.
- Their online activities have increased noticeably since COVID-19.

Source: US NORD online survey of 968 individuals from October 2019 through March 2020



In the last year, Ipsos's Rare Disease CoE has leveraged best-in-class research methodologies and innovative approaches to uncover rare disease insights.

- **70+** custom research projects in North America alone
- Global Therapy Monitors in **7** rare indications (ATTR-CM, ATTR-PN, Hemophilia, SCD, PAH, HAE & PN)
- Global Oncology Monitor in multiple rare cancer types
- **14** social listening projects capturing unprompted patient insights in **8** rare diseases.



Ipsos thanks our clients who have made strides in the diagnosis, treatment, and care of rare diseases. We also deeply appreciate the patients and providers who participate in our research programs.

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