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.



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

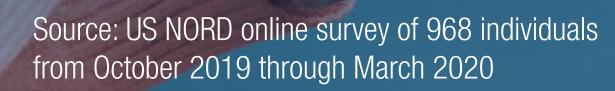
An Ipsos survey in Canada found that patients saw an average of 5.9 different healthcare professionals, received an average of 3.2 wrong diagnoses, and waited an average 3.7 years for an accurate diagnosis.

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.





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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