

Characterizing the patient experience: The role of patient-reported outcomes

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Biological endpoints are essential, but on their own, they cannot tell the full story. To truly understand the value of a treatment and care surrounding it, we must also seek to understand how patients and carers experience it. This is where patient-reported outcomes (PROs) and observer-reported outcomes (reflecting the perspectives of non-clinical caregivers) are becoming more prominent in clinical research.

The value of PROs

PROs give patients a direct voice in clinical research, enabling them to describe the impact of the disease and treatment on their quality of life, daily functioning and symptom burden. When designed and implemented rigorously, PROs provide direct scientific evidence of treatment impact from the patient's perspective, capturing aspects of benefit or risk that are meaningful to patients but may otherwise have gone unseen.

This perspective is particularly important in areas of high unmet need, such as rare diseases, rare cancers and chronic conditions, such as movement disorders. In these settings, even small improvements can have a significant impact, reducing pain or fatigue, improving mobility, restoring sleep or helping patients return to everyday activities. Capturing these important insights through integrating measures such as itch rating scales and fatigue questionnaires in rare liver diseases, as well as using digital health tools can help build a more complete picture of the impact of our medicines across indications.

Working together to accelerate PRO progress

However, there is more to be done. For many rare and complex diseases, disease-specific PRO instruments do not yet exist or are not validated for integration into clinical trial design. Small patient populations and highly variable disease pathways can make tool development challenging, contributing to a gap between clinical data and evidence of patient-perceived benefit.

At Ipsen, we see this as an ongoing journey, one that requires continuous listening, learning and collaboration with patients, caregivers and advocacy communities. By working together, we aim to ensure that patient insights increasingly shape trial design, clinical development, and evidence generation, because behind every data point is a person hoping for meaningful change.

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