

Closing the Gap: How Patient Experience Data Is Revamping Research

Learn how patient input can shape new therapies and provide deeper insight into chronic conditions.



folia
— HEALTH

HOME-REPORTED OUTCOMES



The Importance of Patient Experience Data

Patient experience data (PED) is transforming healthcare, fueling well-attuned, patient-focused research that results in more effective treatments that positively impact the outcomes that matter most to patients.

Prospective observational studies, which follow participants over a designated period of time, can benefit greatly from PED. By incorporating PED, researchers can better understand the full burden of a condition on individuals and the effectiveness of new treatments.

This guide will illustrate the depth PED brings to research, informing sponsors throughout the drug development requirements, launch preparation, and beyond.

Contents

Mind the Gaps	3
Shifting the Focus	4
Accomplish More with HROs	5
Case Studies: How HROs Are Already Impacting Research	6
Conclusion	7

Mind the Gaps

Traditional research methods often leave gaps in understanding that cause rifts in the perceived treatment effectiveness.

Let's explore the challenges faced without PED.



Diverse Patient Populations

Data from traditional clinical trials, with narrow inclusion/exclusion criteria, don't always reflect diverse populations, particularly those from racial and ethnic minority groups. This limits the generalizability of study results and perpetuates health disparities.



Personal Journeys

Research that focuses exclusively on clinical and observer-reported measures of treatment efficacy doesn't capture the broader aspects of disease burden. These methods don't involve the individual experience of a condition or treatment, including personal goals, heterogeneous symptomatology, and impact on mental health, which are key to understanding the full picture of a patient's health.



Treatment Choices

Traditional real-world data (RWD) doesn't contextualize treatment use or non-use, a.k.a. why a patient's choices might not follow the treatment plan. Whether prompted by simple habits or adverse effects, it's hard for researchers to learn and gain insights from behavior outside the clinic.



Long-Term Outcomes

Home-reported outcomes (HRO) account for any health observation reported directly by patients or caregivers outside of the clinic via in-app tracking adjusted to the specific experience of each condition and user. Patients can leverage HROs for better care and contribute HROs to enriched datasets for research.



Symptomology in Response to Therapy

PROs and point-in-time qualitative surveys remain the same over time, not accounting for changes in disease progression in response to therapy. As symptomatology evolves, they fail to capture a realistic and comprehensive understanding of the condition burden.



Unquantifiable Real-World Outcomes

Events like doctor's appointments and ER visits occur in controlled settings. This data fails to provide insight into what happens outside of those settings, making it difficult to assess the condition and treatments fully.

Shifting the Focus: How Researchers Fill the Gaps

Researchers are more acutely aware of the limitations of traditional healthcare data and actively bridging gaps to complete the picture of disease burden, natural history, and therapy impact. **The key is PED.**



Diverse Patient Populations

PED can help fill this gap by providing insights into the experiences of underrepresented racial and ethnic minority groups. Using decentralized research methods, you can meet these individuals where they are rather than requiring them to go to a clinic, making enrollment and long-term engagement easier for underrepresented communities.



Personal Journeys

Every condition and therapy can impact multiple aspects of a patient's overall health, from their mental well-being to changing symptoms. PED captures the complete individual perspective and provides a more nuanced understanding of how patients feel and function in the real world, painting a more accurate picture of the full disease burden.



Treatment Choices

PED around treatment use or non-use can provide greater context into individual behavior and decision making, including preferences or habits. This gives researchers greater insight into possible impediments to effective therapies from those dictating treatment changes.



Long-Term Outcomes

PED collected over time offers valuable insight into the long-term effects of a condition or therapy on an individual's quality of life, functionality, and well-being outside of and after the initial assessment of symptoms or treatment.



Symptomology in Response to Therapy

When the treatment landscape changes, PED captures the response to new drugs, providing a more accurate view of the changes in disease burden and therapy impact over time.



Unquantifiable Real-World Outcomes

PED collected outside clinical settings shines a light on the valuable evidence of treatment effectiveness and safety. Where controlled settings gather controlled data, real settings gather real experiences, leading to a more complete view of symptoms, treatment use, and more.

Accomplish Even More with HROs

We know the value of PED, but the multitude of modern data capture methods can be overwhelming. Home-Reported Outcomes (HROs) bring it all together to make the decision simple. **How?**



Diverse Patient Population

HROs leverage app-based tracking to reach everyone. This level of accessibility takes a deep, patient-focused approach while still reaching the masses, including underserved populations that don't have the time or resources to participate in clinical trials.



Personal Journeys

HROs allow patients to record their unique, individual experiences, taking a more patient-driven approach than traditional data capture methods and allowing researchers to better understand the broader aspects of the full disease burden, including changing symptoms, mental health, personal goals, and more.



Treatment Change

HROs capture data around a patient's use of treatments as prescribed, use over time, and reasons for non-use. Patients can track their unique situation honestly and provide valuable data that would otherwise stay buried.



Long-Term Outcomes

HROs support longitudinal studies, including goal progress, mood and behavioral health, and productivity. This provides a complete view of how the patient feels and evolves over time, which lends itself to more accurate and generalizable condition and treatment insights.



Symptomology in Response to Therapy

HROs are tailored to each user and condition, so when treatment evolves, patient responses follow. They can capture changes in routine, unusual symptoms, the patient experience, and responses to therapy as treatment plans shift over time.



Unquantifiable Real-World Outcomes

HROs capture day-to-day experiences outside the clinic, including at-home acute events and exacerbations, including the incidence and recurrence, characteristics of the event, and resolution. With app-based tracking, HROs can be tracked as close to real-time as the individual wants.

Case Studies:

How HROs Are Already Impacting Research



Therapy Impact

The Goal

A study sponsor approached Folia Health to gather information directly from patients and caregivers on changes in symptoms and treatment while introducing a novel therapy for individuals living with a rare pediatric condition.

The Gap

This organization needed higher resolution data to bridge gaps left by the episodic nature of traditional in-clinic research, showcasing the spectrum of outcomes and emphasizing the therapy's potential to reduce the need for non-disease-modifying chronic daily treatments.

The Solution

Folia recruited from an existing user base and selected clinics, with participants tracking symptoms and treatments over six weeks and providing structured data and qualitative observations. This led to a national rollout and a second eighteen-month study on treatment effectiveness.

Disease Burden & Natural History

The Goal

A study sponsor approached Folia to better understand the experience of those living with a rare hematological condition of high incidence amongst racial minority groups, including the prevalence and burden of acute pain events at both the individual and population levels.

The Gap

Because they're based only around the time points where patients seek care, RWD from claims and electronic health records are not adequate measures of the frequent exacerbated pain events that those living with this condition can experience. This means that without HROs, the incidence and burden of pain events would not be able to be effectively measured.

The Solution

The study used Folia's app and proprietary real-time flare tracking technology to record and assess the day-to-day experience of those living with this condition, measure outcomes, and capture changes in pain severity, which suggested that patients with this condition may experience pain flares more frequently than the current literature proposes.

Conclusion

HROs provide a level of PED previously inaccessible to researchers: individualized and unique data that can be generalized to entire populations and inform the development of new, effective therapies. In other words, HROs ensure the patient has a voice and is at the center of research and development.




CHROMA for life sciences is Folia Health's suite of end-to-end observational and interventional study services. From protocol design to recruitment, study management, data analysis, publication support, and beyond, CHROMA offers a completely patient-driven approach to hybrid or fully decentralized studies. Our CHROMA suite allows life science leaders to overcome common RWD challenges, such as measuring disease burden heterogeneity, comprehensive treatment impact per phenotype, and analyzing flares and exacerbations outside the clinic. Folia provides high-fidelity and high-value insights to study sponsors while allowing patients to use the data they create to inform their care decisions.

About Folia Health

Folia Health is the founder of home-reported outcomes (HROs), the next generation of patient health data that transforms lived experiences outside the clinic into valuable insights for better research and care. Through an innovative platform backed by expert analysis and support from a compassionate team, we help life science partners develop effective therapies with demonstrated, real-world value for complex, chronic conditions.

Contact us today to learn how HROs are expanding healthcare research to produce more patient-focused therapies.



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