A Look Ahead: Patient Health Data in 2023 & Beyond

- **Discover** trends, challenges, and opportunities

- **Understand** differences in patient health data

- **Enrich** evidence strategies with HROs

folia HEALTH

HOME-REPORTED OUTCOMES

Big Data.
Big Opportunity.

Healthcare makes up approximately thirty percent of the world's data volume.[1] It takes on endless forms: electronic medical records (EMRs), genomic data, claims records, biometrics, patient-reported data, and so on. With the rate at which technology is accelerating, there's only more to come. The key to staying on top of it resides in embracing innovative trends and patient preferences.

Let's discuss the top five trends in patient health data for 2023 and how you can make them actionable.

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Deciphering Patient Health Data

First things first. With the proliferation of new health data types over the past decade, it's hard to know what's what. Here's a refresher of terminology:

RWD

Real-world data (RWD) relates to patient health and care delivery and is collected from various sources, including EMRs and administrative or billing claims information. Emerging sources include wearable devices and home sensors.

PRO

Patient-reported outcomes (PRO) are standardized reports of a health condition directly from the patient, without interpretation by a clinician or other professional.

PGHD

Patient-generated health data (PGHD) might include health history, treatment regimen, symptoms, biometrics, and PRO measures. Patients are responsible for capturing and distributing this data to providers and researchers.

HRO

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.

Decentralization & Digitalization

Trend #1: Decentralized Clinical Trials

There has been extraordinary growth in decentralized trials as a method for capturing high-quality data. This has brought immense value to research inclusivity, leveraging remote and hybrid methodologies to tap underserved regions and populations. For pharma and biotech companies, this means meeting patients where they are.

Technology rooted in app-based tracking, like HROs, can reach virtually everyone, inherently complementing decentralized approaches to attaining even greater diversity, equity, and inclusion. This is particularly important in how we measure treatment impact. Sometimes, clinical endpoints are separate from the outcomes most important to individuals living with a condition. Diverse representative samples help foster a complete understanding of disease burden, enabling drug developers to select the right endpoints for their studies that can reflect the true value of a new therapy for the right population. With an estimated 312 million Americans having smartphone access in 2023,[2] more comprehensive and patient-centric studies are at our fingertips.

Trend #2: Digitalization of Patient-Collected Data

While much patient data is digital and structured, there's an overwhelming amount of information collected by patients and their families in spreadsheets, notebooks, and binders.

HROs were created upon realizing there wasn't a place for patients to track day-to-day observations in a structured and actionable format—or a method for researchers to access them. **This information can inform critical initiatives to improve clinical development and commercial success.** HROs provide space for patients to track daily experiences, uncovering relevant insight for unique research objectives.

The world is rapidly recognizing the importance of digitizing unstructured records to break down silos.

Patient Participation

Trend #3: Patient Centricity

Involving patients and caregivers earlier in the drug development process is growing in prevalence. Traditionally, we've focused on clinician assessment and device measurement over patient reporting to establish an understanding of outcomes, particularly in research settings. This creates a reliance on extreme flares, interval checkups, and intel from other standard sources. But what about the day-to-day experiences of living with a particular condition? Without this feedback, you risk lacking evidence around real-world needs.

Patients should have a direct impact on the new therapies developed for them.

HROs capture a high volume of personal knowledge, putting the needs and opinions that matter most at the center of decision making every step of the way. With depth in patient-generated insights comes trial success, product uptake, and positive health outcomes.

Trend #4: Permissions & Ownership

With big data consuming life sciences—and decentralization and digitization showing no signs of slowing—privacy has never been more important. People have always been skeptical about where personal health information is going and what it's used for, but they shouldn't have to question it. **The most effective ways to build trust are transparency, permissions, and ownership.**

Data sharing permissions and patient ownership are at the very core of HROs. **They put the patient in the driver's seat with total control over whether they want to share data with the research community or just utilize it for care management.** As a researcher, it's critical to leverage technology you and the user can trust. It's a direct channel for strengthening patient relationships, encouraging long-term participation, and fueling successful studies.

Longitudinal Data

Trend #5: Longitudinal Data

Longitudinality allows exploration of dynamic rather than static concepts.[3] In recent years, there have been attempts at compiling disparate data sources, like clinical trial data, EMR genomic data, claims records, biometrics, and beyond. However, researchers are still left with gaps. **Now, they're turning to newer methodologies that integrate patient preferences, risks, and needs to better understand the progression of conditions and treatment impact over time.**

HROs provide just that: longitudinal observations of symptoms, outcomes, and care, offering a higher volume of data points per participant than current methods. **This enriched, multilayered dataset tells the complete story—not just partial—and becomes the complete, real-world snapshot of an individual's health.**

- Claims

HROs

- EMRs
- Lab Results
- Genomic Data

- Clinical Trial Data
- PROs
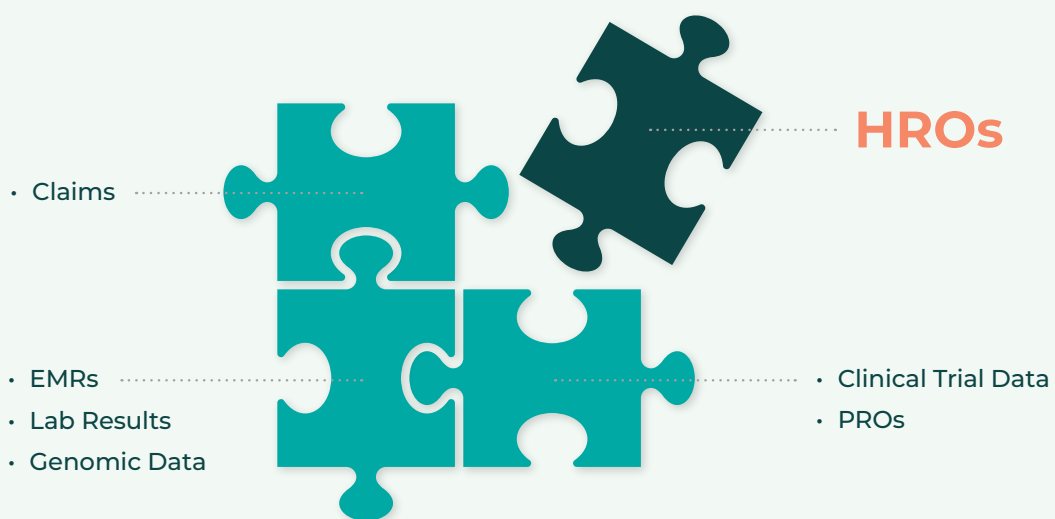
Do More with Patient Data

Folia Health is the founder of HROs, the next generation of patient health data that transforms lived experiences outside of the clinic into valuable insights for better research and care. How? By staying on the edge of innovation.

- **Decentralized Clinical Trials:** Folia reaches underserved regions and populations via highly accessible app-based tracking as its primary data collection method.

- **Digitalization of Patient-Collected Data:** Folia's app empowers users to track everyday health experiences like never before, filling the day-to-day data gap in research.

- **Patient Centricity:** Folia positions patients as the focal point of decision making, resulting in research fueled by evidence around real-world needs.

- **Permissions & Ownership:** Folia's unwavering dedication to patient ownership lends itself to strong relationships, long-term participation, and well-informed data.

- **Longitudinal Data:** Folia provides an enriched, multilayered dataset that tells the complete patient story for better results.

We help life science partners develop effective therapies with demonstrated, real-world value for complex, chronic conditions. **Looking for compassionate, scientific support? Collaborate with experts in HRO collection and analysis.**

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Sources:

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