

WHITE PAPER

Following Rare Disease Patients Across Payer Transitions

A Real-World Data Perspective on
Longitudinal Continuity for Research
and Commercial Strategy

Rare disease patients frequently move between Medicaid, Medicare, and commercial insurance throughout their care journey. Pediatric onset, slow progression, and disability pathways combine to make payer transitions more common in rare disease populations than in most other therapeutic areas.

For HEOR, RWE, and commercial teams, these transitions create a significant challenge. When patient records cannot be linked across coverage changes, researchers may lose visibility into treatment patterns, healthcare utilization, outcomes, and provider relationships. The result can be incomplete patient journeys, undercounted populations, fragmented longitudinal studies, and missed commercial opportunities.

The ability to follow rare disease patients across payer transitions is often the difference between observing part of the journey and understanding the full continuum of care.



Why Rare Disease Patients Experience More Payer Transitions

Rare disease patients experience payer transitions more frequently than many other patient populations due to a combination of pediatric disease onset, disability-related coverage changes, treatment economics, and enrollment churn.

Several characteristics, taken together, make rare disease cohorts especially exposed to payer transitions.

Pediatric onset

Approximately [70% of rare diseases manifest in childhood](#) globally, according to EURORDIS analysis of the Orphanet database.

[Children represent close to half of all Medicaid enrollees](#) in the U.S., meaning a substantial share of rare disease patients enter the healthcare system through Medicaid or Children's Health Insurance Program (CHIP) rather than through commercial coverage.

Disability pathways

Progressive conditions including Duchenne muscular dystrophy, spinal muscular atrophy, transthyretin amyloidosis, and complications of hemophilia frequently meet the eligibility criteria for Social Security Disability Insurance (SSDI).

SSDI eligibility provides a route to Medicare coverage before age 65, often with concurrent Medicaid eligibility under dual coverage rules.

Treatment economics

Annual costs for rare disease therapies regularly reach six and seven figures.

[Medicaid spending on rare-disease gene and RNA therapies](#) grew from approximately \$148 million to \$880 million between 2017 and 2022, almost entirely driven by SMA and DMD treatments. As a result, significant portions of these patient populations are concentrated within Medicaid.

Eligibility churn

Coverage is not always continuous even within a single payer type. Pre-pandemic data indicate that approximately [10% of full-benefit Medicaid beneficiaries experienced a coverage gap](#) of less than one year.

The pandemic-era continuous enrollment provision suppressed this churn temporarily. Its unwinding subsequently [disenrolled more than 25 million people](#), of whom approximately 70% lost coverage for procedural rather than eligibility-related reasons.

The cumulative effect is statistical. A rare disease patient’s claims footprint is more likely to span multiple payer types than that of a typical commercially insured patient. Studies and patient-finding analyses that draw from a single payer type, or from a single commercial data source, begin at a representational disadvantage that compounds over the duration of the study or analysis.

How Payer Transitions Manifest in Claims Data

Rare disease patients move along several common transition paths. A few of those transitions appear very different in claims data than the underlying policy categories would suggest.

Transition Pathway	Common Rare Disease Examples	Key Data Challenges
Pediatric Medicaid/CHIP → Adult Coverage	DMD, SMA, hemophilia, metabolic disorders	Record fragmentation
Commercial → Medicaid	Progressive diseases affecting employment	Coverage gaps
Commercial → Medicare (<65) via SSD	DMD, BMD, SMA, ATTR, hemophilia	Significant longitudinal discontinuity
Commercial or Medicaid → Medicare (65+)	ATTR and later-onset diseases	Loss of treatment visibility

Pediatric Medicaid or CHIP to adult coverage

The most common pediatric transition pathway involves conditions diagnosed in early childhood, including DMD, SMA, hemophilia, and hereditary metabolic disorders.

Around age 19, patients typically shift to a parent's commercial plan, the ACA marketplace coverage, or remain on adult Medicaid depending on state, income, and disability status.

An important nuance affects how this transition appears in claims data. In most states, [CHIP in most states is delivered through private managed care organizations](#), the same insurers (Aetna, Centene, Elevance, Molina, UnitedHealth) that administer Medicaid and commercial coverage. A child enrolled in a separate CHIP program may therefore appear in claims under a commercial-style carrier brand, even though the underlying coverage is government-funded.

When that patient later transitions into Medicaid, the data may show what appears to be a commercial-to-government transition that does not reflect a true change in coverage source, only a change in how the same family of payers reports the patient.

Without patient-level linkage across these segments, a single transition can appear in data as two unrelated patient records.



Commercial to Medicaid

As disease severity increases caregiving demands and disrupts income, families frequently move toward Medicaid coverage.

The transition rarely happens cleanly. Marketplace coverage, COBRA, and short-term coverage gaps are common waypoints between commercial employer-sponsored coverage and Medicaid eligibility.

Commercial to Medicare under age 65

This pathway is particularly relevant for rare disease populations.

Patients under age 65 do not typically qualify for Medicare, but they can reach it through disability. A patient first applies for and is approved for SSDI, which requires demonstrating an inability to engage in substantial gainful activity due to a medically determinable impairment. After a five-month waiting period from the established disability onset date, SSDI cash benefits begin. [After an additional 24-month qualifying period](#), the patient is automatically enrolled in Medicare, totaling approximately 29 months from disability onset to Medicare eligibility. In practice, the timeline is often longer because initial disability applications may be denied and later appealed.

Patients with amyotrophic lateral sclerosis (ALS) or end-stage renal disease are exceptions, bypassing the 24-month waiting period and receiving Medicare immediately upon SSDI approval. For rare disease populations, this pathway is more common than it is in the general under-65 population.

Progressive neuromuscular conditions (DMD, BMD, adult SMA), advanced transthyretin amyloid cardiomyopathy and polyneuropathy, severe sickle cell complications, and hemophilia with significant joint damage all commonly meet SSDI criteria. Many patients retain Medicaid as a secondary payer under dual-eligibility rules, generating both Medicare and Medicaid claims simultaneously.

From a data perspective, this transition often creates the most significant source of discontinuity. The same patient may appear initially as a commercially insured adult, disappear from data feeds for 24 months during the Medicare waiting period (covered variously by COBRA, marketplace plans, Medicaid, or no insurance), then reappear as a Medicare Advantage member, often under a different carrier brand entirely.



Commercial or Medicaid to Medicare at age 65

For later-onset conditions such as wild-type ATTR cardiomyopathy, the standard Medicare transition may occur close to diagnosis or treatment initiation.

Studies that observe patients only through the age 65 risk missing a substantial portion of the active treatment journey.

Why this matters

Each transition introduces the potential for discontinuity in the longitudinal patient record. In rare disease populations, every patient lost to discontinuity matters. Small populations amplify the impact of attrition much more quickly than many researchers and commercial teams assume.

Implications for HEOR and RWE Study Design

Payer transitions affect several specific study designs in ways that are not always immediately visible in the data.

Natural history studies

Natural history studies depend on multi-year pre- and post-diagnosis observation windows.

A payer transition at the wrong point in the timeline can shorten the effective observation period or fragment a patient record into separate, unlinked records.

External control arms

External control arm construction for single-arm trials requires confirmed continuous observation across the treatment journey.

Patients who disappear from data following a payer change cannot anchor a defensible synthetic comparator. The resulting cohort may become biased toward patients whose coverage remained stable.

Persistence and adherence studies

Treatment persistence and adherence research depends on uninterrupted visibility into fills and administrations.

A four-month coverage gap in the wrong data source does not represent a real-world adherence pattern. It represents missing data that appears as non-adherence.

Diagnostic odyssey research

Pre-treatment journey reconstruction often spans four to six years or longer.

Few rare disease patients remain within a single payer environment for that entire period, making continuity essential for understanding the full path to diagnosis.

Burden-of-illness studies

Research comparing healthcare resource utilization before and after diagnosis depends on stable observation windows on both sides of the diagnosis event.

Payer transitions can compromise those comparisons.

The common challenge

In each case, the issue is not simply statistical bias that can be adjusted after the fact. It is missing patients and missing data that researchers may not realize are missing.



Implications for Commercial and Patient-Finding Strategy

The same data discontinuity that constrains research design also constrains commercial functions, often in ways that appear as a quietly smaller addressable market rather than as obviously missing data.

Patient finding

Patient-finding analyses systematically undercount eligible patients when based on single-source data.

A patient identified in commercial claims who transitions to Medicare disappears from a commercial-only data feed. Likewise, a patient identified in Medicaid who ages out of pediatric coverage onto a parent's commercial plan disappears from a Medicaid-only feed. In both cases, the patient remains real and continues to receive treatment but becomes invisible to the analytic source being queried.

Prescriber footprint analysis

Prescriber footprint analyses are similarly affected.

The treating physician often changes when a patient's coverage changes, particularly during transitions from pediatric to adult care or when a Medicare Advantage network differs from a prior commercial network. A data source that loses the patient through a transition also loses visibility into the next provider in that patient's journey.

Account-based commercial planning

Account-based commercial planning understates institutional volume when the underlying data is restricted to a single payer type.

Health systems and academic medical centers treat rare disease patients across all coverage types. A view limited to commercial claims systematically underrepresents the centers seeing the highest concentration of patients, particularly those serving Medicaid-heavy or dual-eligible populations.



Diagnostic odyssey mapping

Diagnostic odyssey mapping, which has commercial value for targeting referral patterns and educational outreach, fragments at payer transitions.

If the odyssey crosses a coverage event, single-source data divides the picture into a “before” and an “after” with no link between them.

Geographic and regional planning

Geographic and regional analyses understate patient concentration in areas with high Medicaid penetration.

Rural regions and urban safety-net catchments drop out of commercial-only views, biasing regional planning toward higher-income geographies.

The common challenge

The common thread across these effects is structural. The consequence is not a measurable bias the analyst can correct. It is patients, providers, and institutional accounts the analyst does not know are missing.

How Linked Closed Claims Preserves Longitudinal Continuity

Inovalon's closed claims dataset is sourced directly from health plans and pharmacy benefit managers across Medicaid, Medicare Advantage, and commercial payer types. Because the data is linked at the patient level across these sources, a patient who transitions from Medicaid into a commercial plan, or from commercial coverage into Medicare Advantage, can be followed continuously rather than restarting as a new record at each transition.

The longitudinal continuity is not an analytic adjustment applied after data ingestion. It is a property of how the data is sourced and linked at the patient level. That structural property is what makes the dataset usable both for research designs requiring continuous observation windows and for commercial workflows that depend on remaining with the patient as coverage changes.

Why continuity matters more in rare disease

The smaller the starting cohort, the more each lost patient costs the analysis. A 15% attrition rate from payer transitions is manageable in a study of 50,000 commercially insured patients with diabetes.

The same attrition rate in a confirmed-SMA population of 800 can render a HEOR study underpowered before analysis begins or shrink a commercial addressable market estimate by enough to miss a region entirely.



A **15% attrition rate** may have limited impact in a diabetes study with **50,000 patients**. The same attrition rate in a confirmed SMA population of **800 patients** can materially affect study power, cohort construction, and market estimates.

Complementary data assets

Closed claims capture one layer of the patient record. For research and commercial questions that require broader population reach, such as patient finding at scale, prevalence estimation, or prescriber and regional treatment-pattern mapping, Inovalon's open claims is a separate asset that complements closed claims with wider cross-payer breadth.

For questions that require clinical detail not captured in claims, including lab values, biomarker results, performance status, imaging findings, and symptom severity, Inovalon's structured EHR and clinical notes assets complement claims with patient-level clinical depth. Each is sourced and linked under its own methodology, scoped to a different category of question.

Evaluating Data Sources for Rare Disease Work

The questions worth asking of any real-world data source supporting rare disease work concern the structural properties that determine whether patients can be followed across coverage events.

The areas to explore in a feasibility conversation include:



Source provenance



Linkage methodology



Cross-payer match performance for the specific indication under study



Record currency and lag



Indication-specific footprint across the payer types most relevant to the patient population

These are not questions a standard data sheet can answer particularly well because the right answer depends on the patient population being studied.

Match rates, data currency, and payer coverage vary by indication and by the payer mix in which the population concentrates. A feasibility assessment built around specific inclusion criteria, payer distribution, and study objectives is often the most effective way to determine whether a data source can support a particular research or commercial use case.

Indication-Specific Applications

Cross-payer longitudinal continuity is especially important for several categories of rare disease research.

Duchenne Muscular Dystrophy (DMD) and Becker Muscular Dystrophy (BMD)

For long-term outcomes research following Elevidys and other gene therapy administration, post-treatment observation must span pediatric-to-adult coverage transitions to be meaningful. Maintaining continuity across payer types is essential for understanding outcomes over the full duration of follow-up.

Spinal Muscular Atrophy (SMA)

For treatment persistence and switching analyses across Spinraza, Zolgensma, and Evrysdi, observation must extend across the Medicaid-to-commercial-to-Medicaid pathways common in pediatric-onset populations.

Without cross-payer continuity, treatment journeys may appear incomplete, obscuring persistence and switching patterns over time.

Transthyretin Amyloidosis (ATTR)

For patient-finding and diagnostic delay research, the four-to-six-year period between symptom onset and diagnosis almost always spans at least one payer transition for older adult populations.

The diagnosing cardiologist or neurologist often sits in a different network than the symptom-stage primary care provider, making cross-payer continuity critical for reconstructing the full patient journey.

Hemophilia A and B

For treatment pattern research and provider mapping, observation must extend as patients age into different coverage types and as new prophylactic and gene therapies enter the treatment landscape.

Longitudinal continuity helps preserve visibility into evolving treatment pathways and provider relationships.

External Control Arm Construction

For rare disease single-arm trials seeking regulatory or health technology assessment (HTA) defensibility, external control arm construction depends on continuous observation across the treatment journey.

Cross-payer linkage helps maintain the longitudinal visibility required to support robust comparator cohorts.

Center-of-Excellence Identification and Commercial Planning

For indications concentrated within a small number of high-volume institutions, center-of-excellence identification and account-based commercial planning require cross-payer visibility into the populations those institutions actually serve. Limiting analysis to a single payer type can underrepresent institutional volume and patient concentration.



Why Continuity Matters for Rare Disease Patients

Rare disease populations move between payer types more frequently than most other patient populations, driven by pediatric onset, disability pathways, treatment economics, and eligibility churn. Real-world data sources that lose patient continuity at coverage events systematically undercount these populations and fragment longitudinal records.

For HEOR, RWE, and commercial teams in life sciences, the structural properties of the underlying data source determine whether key research and commercial questions can be answered defensibly.

Patient-level linkage across closed claims sources from Medicaid, Medicare Advantage, and commercial payer types is the foundation for studies and analyses that depend on following patients across the full arc of their care.

Where claims alone cannot answer the question, complementary data assets, including open claims for broader population reach and structured EHR and clinical notes for clinical depth, extend visibility to the dimensions of the patient record that matter for the specific use case. For rare disease work specifically, this matters more than for any other therapeutic area. The populations are small, the transitions are common, and the cost of losing a single patient to data discontinuity is high.

Support longitudinal patient visibility across payer types and care settings.
[Discover Inovalon's Real-World Data™](#)

About us

Inovalon is a leading provider of data and solutions empowering data-driven healthcare. We bring together national-scale connectivity, real-time primary source data access, and advanced analytics into a sophisticated platform empowering improved outcomes and economics across the healthcare ecosystem. The company's analytics and capabilities are used by over 50,000 active, licensed customers. For more information, visit www.inovalon.com.

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