

"val_b": 67.2,
"val_c": 1012.3,
"vec": [5.1, -2.9],
"qual": {"p": 15.8, "q": 22.1, "r": 45.6}

THE MISSING LINK IN RARE DISEASE ANALYTICS:

Patient Journey Visibility

For rare disease teams, the biggest challenge isn't just finding patients — it's seeing where individual journeys break down.

Introduction

A rare disease patient may be identified long before they ever start therapy.

A physician may recognize the signs, lab work may point in the right direction, and an enrollment form may already be in motion. But even then, the path from diagnosis to start of therapy often slows down.

The delay could sit with benefits investigation, prior authorization, reimbursement, or a specialty pharmacy handoff. One team may see the details behind the barrier, while another may only see that an HCP office needs support.

**For the patient, the delay feels personal.
For the organization, it creates an operational blind spot.**

That is what makes rare disease analytics different. The challenge is not just finding patients or building better dashboards. It is giving each team the right level of insight into where individual patient journeys are delayed, so they can coordinate support and help move patients toward therapy faster.

To do that, rare disease organizations need to connect fragmented data, define patient journey stages consistently, and deliver role-appropriate visibility across the teams involved in diagnosis, enrollment, reimbursement, and start of therapy.



Finding the patient is only the first challenge



In rare disease, the first challenge is often finding the patient.

Small patient populations can be difficult to identify, and [diagnosis may take months](#). By the time a patient reaches the right HCP, there may already have been a long path of symptoms, testing, referrals, and uncertainty.

But identification is only one part of the challenge.

Once a rare disease is suspected or diagnosed, the HCP office may need education on the disease state, the diagnostic process, and the treatment protocol. That support often extends beyond the physician. Office staff may also need to understand how enrollment works, what information is required, and how the patient moves from diagnosis toward beginning treatment.

Analytics has to account for that complexity. It is not enough to know that a patient exists or that an HCP has potential patients. Teams need to understand where the journey is slowing and what still needs to happen.

The population is smaller, the journey is more individualized, and the number of touchpoints can be much larger than it appears from the outside.

The gap between diagnosis and start of therapy



Rare disease leaders already know the path from diagnosis to treatment is rarely straightforward.

The challenge is that the handoffs across enrollment, benefits investigation, [prior authorization](#), reimbursement, hub services, and specialty pharmacy partners are not always visible in one consistent view. One team may know a patient is delayed. Another may only see activity at the HCP level. A partner may classify the barrier one way, while another uses different terminology for the same issue.

That creates a gap between knowing patients are moving through the journey and understanding where that movement has slowed.

For commercial, reimbursement, and field teams, that distinction is important.

A patient who has been identified but not yet started therapy may need office education, reimbursement support, hub follow-up, specialty pharmacy coordination, or some combination of those actions.

Without clearer visibility, teams can lose time figuring out where the barrier sits before they can determine who is best positioned to help move the process forward.



When every system tells a different part of the story

Those handoffs become harder to manage when the underlying data is scattered across systems. The issue is not always a lack of data. Rare disease teams may already have claims, labs, CRM activity, hub updates, specialty pharmacy data, reimbursement workflows, and enrollment information.

One system may suggest a patient is moving toward diagnosis. Another may show an enrollment form in progress. A specialty pharmacy may use one status to describe a

delay, while another uses different terminology for a similar issue.

Without a consistent way to connect and interpret those signals, teams are left piecing together the journey from disconnected inputs. They may know activity is happening, but not whether the patient is close to starting therapy, waiting on reimbursement, delayed by a hub process, or stuck in a specialty pharmacy handoff.

That gap slows decision-making because teams have to interpret the journey before they can coordinate the next step.

More access is not the answer

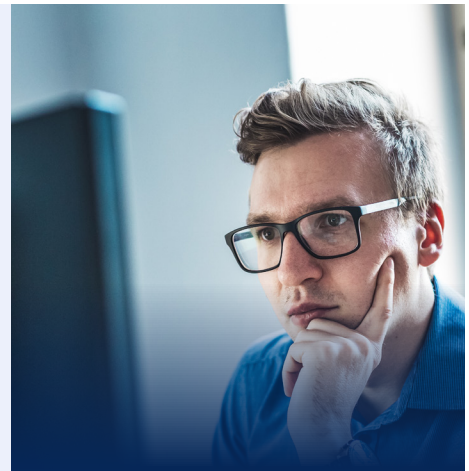
Rare disease organizations cannot solve this by giving every team the same level of detail.

Field teams may need to understand which HCP offices are facing barriers, but they cannot discuss specific patients. Reimbursement, hub, specialty pharmacy, medical affairs, and market access teams may each have different roles in helping patients move forward, along with different levels of access to patient information.

That makes the data model just as important as the dashboard. The organization needs a way to separate what each team can access, what each team can act on, and how those insights should be delivered.

For example, a field team may be able to see that an HCP office has multiple patients delayed somewhere between enrollment and beginning treatment. That signal can help the field team understand that the office may need education or process support. But the field team should not see who those patients are or discuss patient-specific details with the HCP.

For reimbursement teams, that context may be more detailed: whether the delay is tied to benefits investigation, prior authorization, hub follow-up, or a specialty pharmacy handoff.



The goal is not to make the full patient journey available to everyone. It is to give each team the context it needs to support the next step without creating inappropriate access or conversations.

From disconnected signals to coordinated action

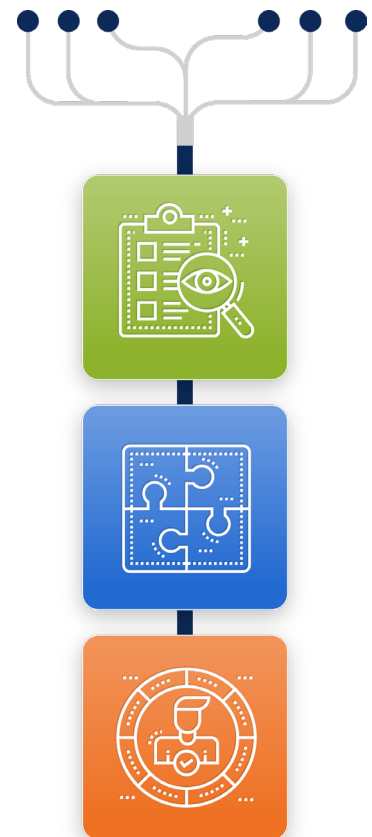
A trusted data foundation helps rare disease teams turn scattered activity into coordinated action.

That starts with connecting touchpoints across systems. Claims, labs, CRM activity, enrollment data, reimbursement workflows, hub updates, and specialty pharmacy information may all offer useful inputs. But those inputs need to be tied together. But those signals need to be tied together in a way that shows how they relate to the same HCP, office, patient journey, or access barrier.

Consistent definitions are just as important. If one specialty pharmacy labels a patient status one way and another uses different language for the same delay, teams need a shared way to interpret those updates. Otherwise, reporting may show activity without showing what the activity means.

This is where [MDM](#), refreshed dashboards, and governed reporting can help. They create a more reliable structure for understanding where patients are in the journey, which teams are already involved, and where the next point of support may be needed.

The value is not just cleaner data. It is helping teams move from “*what is happening?*” to “*what should we do next?*”





Prediction only works when the foundation is ready

Predictive insights can help teams identify likely enrollment patterns and prioritize where support may be needed. But those insights are only useful when they build on connected, governed data that teams can trust.

For rare disease leaders, the takeaway is simple: **analytics should start with the patient journey, not the dashboard.**

When teams can understand where patients are delayed, who can act, and what information each role should receive, they are better equipped to coordinate support and help move patients to therapy.

References: 1. Faye, Fatoumata, et al., "Time to diagnosis and determinants of diagnostic delays of people living with a rare disease: results of a Rare Barometer retrospective patient survey," *European Journal of Human Genetics*, September 2024.
2. Gabriel, Meghan Hufstader, et al., "Specialty pharmacy turnaround time impediments, facilitators, and good practices," *Journal of Managed Care & Specialty Pharmacy*, November 2022.

About **Conexus Solutions**

We combine deep industry knowledge with specialized talent to support progress for pharma and life sciences companies. Our team brings practical experience in commercial operations and technology, helping organizations strengthen capabilities, navigate change, and deliver results efficiently. By aligning strategy with the right tools, we help clients reduce risk, respond to evolving market demands, and build long-term value.

Schedule a consultation at cnxsi.com.



The **team** behind your **team**.



(609) 536-6009
info@cnxsi.com
cnxsi.com