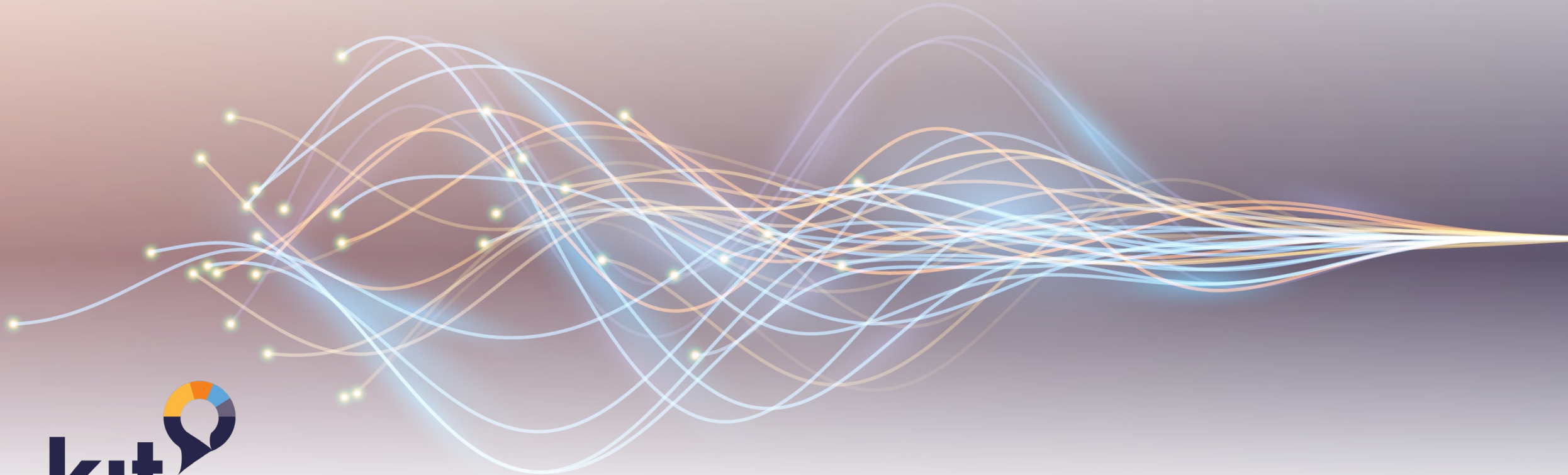


# **Bridging Communication Gaps in Rare Disease Care**

A practical framework for identifying breakdowns  
and translating insight into action



# Communication gaps in rare disease are not just interpersonal. They are structural.

In rare disease care, communication breakdown is often treated as a matter of clarity or bedside manner. In reality, **it is far more complex.**

Patients and physicians are navigating uncertainty, time constraints, fragmented care systems, and fundamentally different definitions of progress. These factors shape not only what is said, but what is heard, understood, and acted upon.

As a result, two can leave the same interaction with very different interpretations of what the condition means, what the treatment is expected to do, what success looks like, what happens next.

Improving communication in rare disease requires more than clearer messaging. **It requires a deeper understanding of where alignment breaks down across the care journey, and why.**

Where the gap forms

Diagnostic uncertainty

Fragmented care

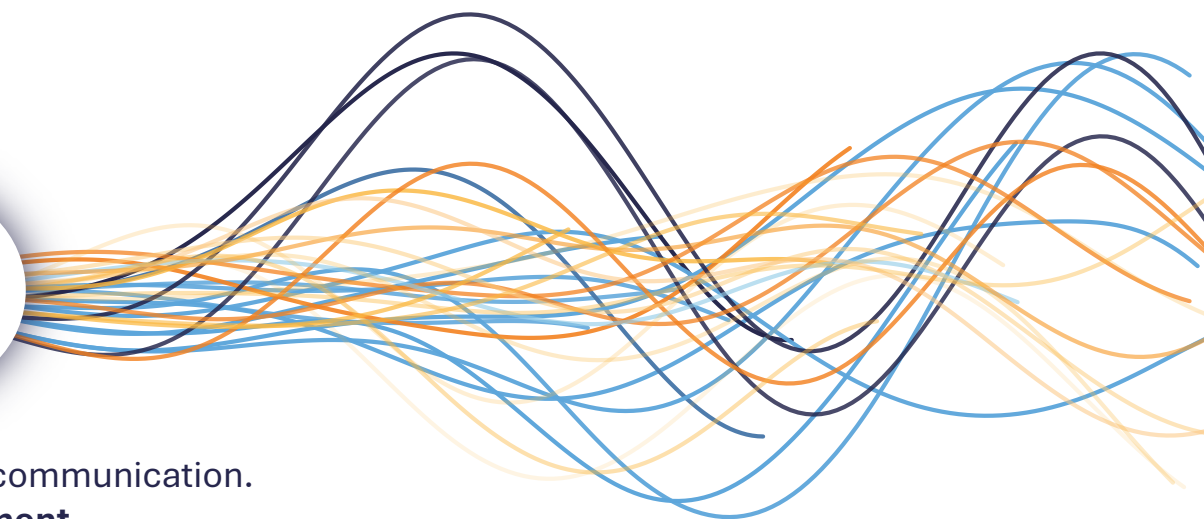
Time constraints

Emotional burden

Misaligned expectations



The challenge is not just communication.  
**It is misalignment.**



# Insights from patients and physicians reveal consistent, but often overlooked, points of disconnect.

**Patients** described communication challenges that extend far beyond a single appointment.

Symptoms are dismissed or minimized early in the journey

The same story must be repeated across multiple providers

Referrals, testing, & follow-up feel fragmented & difficult to navigate

Rushed appointments limit the ability to fully explain experiences

Medical language can feel overwhelming or unclear

Advocacy becomes the (already burdened) patient's responsibility

*"I had to keep explaining everything over and over again, and still didn't feel heard."*

**Physicians** face a different, but equally complex, set of challenges.

Patients & providers may define treatment success differently

Limited time restricts explanation & confirmation of understanding

Clinical language can create unintended barriers

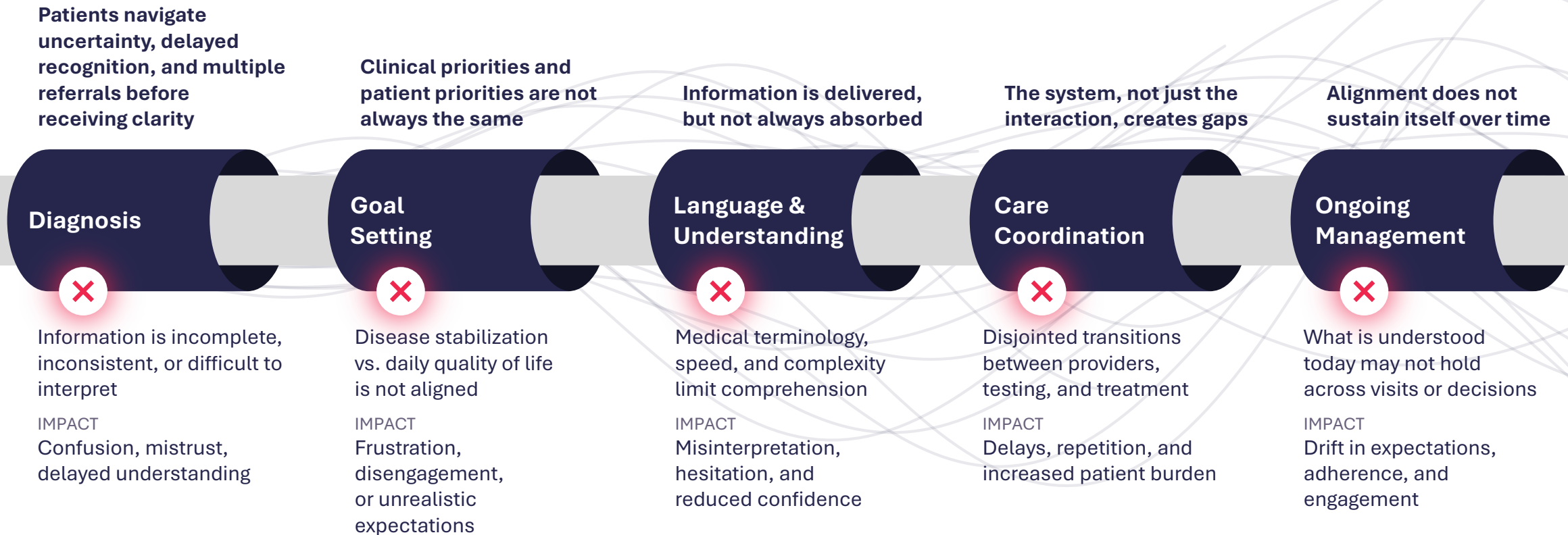
Patients may hesitate to ask questions or admit confusion

Social, financial, & system constraints shape what is feasible in care

It is often unclear whether patients truly understand key information

*"We may be aligned clinically, but not aligned in expectations."*

# Communication gaps are not random; they tend to emerge at predictable points across the care journey.



# Improving communication is not about saying more. It is about ensuring shared understanding.

## Establish a shared foundation

Patients need a clear, accessible understanding of their condition and care pathway from the start.



## Use language that supports action

Information should be understandable, memorable, and usable outside a clinical setting.



## Align on what matters most

Clinical outcomes and lived experience must be addressed together, not separately.



## Confirm understanding, don't assume it

Checking comprehension is essential to meaningful communication.



## Reinforce across touchpoints

Alignment must extend beyond the visit into ongoing care and support.

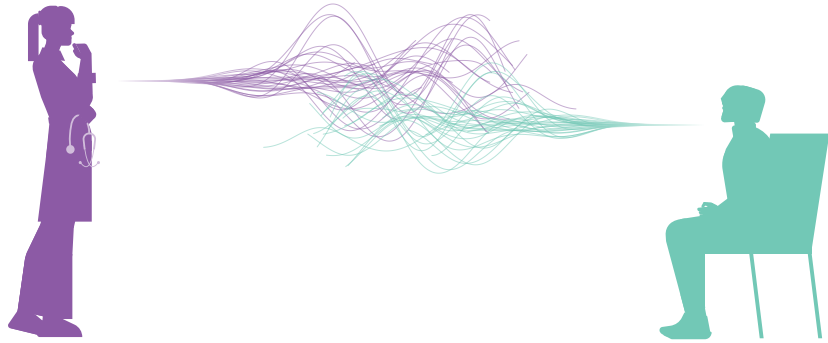


**Clarity is not enough.  
Alignment is the goal.**

# Traditional research often captures patient and physician perspectives independently. While valuable, this approach can miss a critical dimension: what happens within the interaction itself.

Communication breakdown does not occur in isolation.

It occurs in the space between what is said, what is heard, and what is interpreted.



To fully understand these gaps, it is necessary to examine:

- The interaction itself
- How each party experienced it
- Where alignment diverged

## A more complete view of communication

DialogueDx is designed to uncover where understanding breaks down, and why, by analyzing real-world interactions and the perspectives that follow them.



**Observe**  
real patient-  
provider  
interactions



**Interpret**  
how each side  
understood  
the exchange

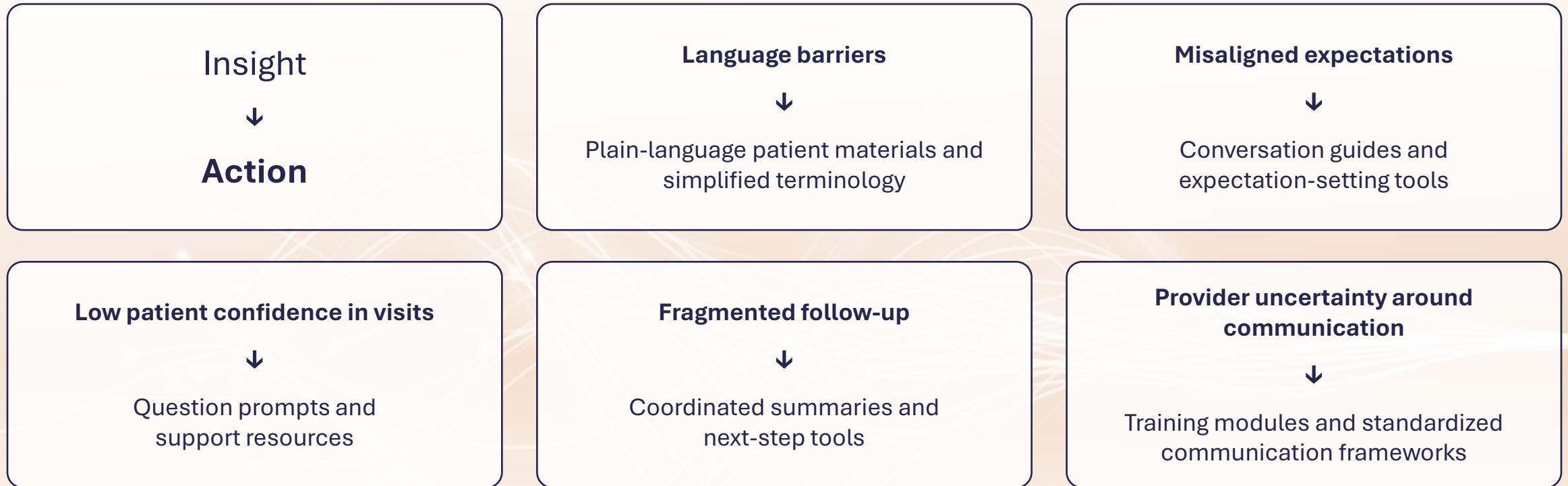


**Translate**  
disconnects  
into insight



**Improve**  
communication  
tools, strategies,  
and support

# Understanding where communication breaks down is only valuable if it leads to action.



Small changes in communication can lead to meaningful improvements in understanding, engagement, and care experience.

# **Communication breakdown in rare disease is not just a clinical issue. It has direct implications for how therapies are understood, adopted, and experienced.**

Organizations that better understand these gaps can:

- Design patient support materials that reflect real-world needs
- Improve alignment between clinical messaging and patient expectations
- Strengthen the effectiveness of physician communication tools
- Inform more patient-centered research and evidence generation
- Identifying intervention points across the full care journey

**Better communication drives better understanding.**

**Better understanding drives better outcomes.**

# Better communication starts with understanding where alignment breaks down.

Improving communication in rare disease care requires more than good intentions. It requires a structured approach to identifying where understanding diverges and translating those insights into action.

At KJT, we partner with life sciences organizations to uncover these gaps and develop evidence-driven solutions that reflect real-world experiences.

**Let's take research further, together.**

Learn more at [kjtgroup.com](https://kjtgroup.com)

