



**Survey Fatigue Is  
Rising Fast in the Rare  
Disease Community  
& Researchers Must  
Act Now.**

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## **What is Survey Fatigue?**

Families living with complex or rare conditions are carrying heavy loads.

When multiple teams send multiple surveys, it adds pressure to people already stretched thin.

**When life is already heavy, even a “quick form” can feel like one task too many.**



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## Understanding the Realities

Multiple research teams often ask the same families the same questions. There's little coordination, and the emotional load behind every answer is rarely acknowledged.

**Behind every response is a parent juggling care, work, appointments and exhaustion.**



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## The Impact on Families

Survey fatigue doesn't mean people don't care. It means they're stretched, exhausted and trying to survive daily life while still wanting to help.

**Ask only what you truly need.  
Design with empathy, not  
convenience.**



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# How Researchers Can Do Better?

**Respect people's time.**

Value lived experience as much as other data points.

**When research is considerate, participation becomes possible and above all meaningful.**

# Thank You

We help health, research and community organisations build real, meaningful relationships with the people they serve.

We strengthen involvement, grow stronger projects and support sustainable funding.

Our expertise in PPIE, Asset Based Community Development, funding strategy and drives lasting impact.

Explore our toolkits: **Beyond Tokenism, Deepening Co-creation and Safeguarding research integrity**

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## Contact Us

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