



NCARDS: **The Rare Disease Data Backbone We Cannot Afford to Ignore**

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The Problem

Rare disease patients are often invisible in the system.

Fragmented pathways, delayed diagnosis and inconsistent access to brand-specific medication make care unsafe and unpredictable.



The Solution

NCARDRS collects and connects rare disease data across England.

It brings together information from maternity units, specialist clinics, labs and hospitals to build a complete picture of each condition.



Why It Matters

Better data means better care.

NCARDRS helps clinicians understand patterns, supports research, informs NHS planning and reduces the burden on patients who currently hold the tentacles themselves.



Call to Action

**Support rare disease data.
Strengthen the safety net.**

Accurate information, consistent documentation and shared responsibility help ensure patients are recognised, not overlooked.

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 a drives lasting impact.

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

Contact Us

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