

Is This NHS Blind Spot Holding Back Rare Diseases?





Why GP Data Matters

GPs hold the richest picture of a person's long-term health. For rare diseases, this includes early symptoms, repeated visits, missed patterns and years of lived experience.

Yet GP data is often under-used in national planning and service design.



Why the NHS Doesn't Fully Use It?

GP data is fragmented across thousands of practices, recorded in different ways and not always linked to hospital systems.

Privacy rules, technical barriers and inconsistent coding make it harder to use at scale.

The result: national datasets often rely more on hospital data than primary care.



Impact on Rare Diseases

Rare disease journeys usually begin in primary care. When GP data is missing, early warning signs disappear from the national picture.

This leads to under-counting, delayed diagnosis and services that don't reflect real-world need.



Why Fair Data Must Include GPs

Fair Data means every community is visible in the data that shapes care.

For rare diseases, that visibility starts in GP records.

Linking GP and hospital data would transform understanding, improve pathways and reduce diagnostic delay.

Thank You

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

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

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