



QS214: What It Really Means for People Living With Rare Diseases

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What is QS214 ?

QS214 is the **NICE Quality Standard for Rare Diseases.**

It sets out what good care should feel like for people like us.

It promises earlier recognition, faster diagnosis, a named coordinator and joined up support.

QS214 recognises that we should not have to fight for basic care.





Why QS214 Matters?

QS214 is not just another NHS document, it's a line in the sand.

For people like us, it is a promise that care should feel safe, dignified and human.





QS214 says: Listen First!

QS214 starts with listening.
People often know more about
their condition than the
professionals.

Lived experience is expertise.





What We Keep Saying

"I'm exhausted of repeating myself."
"I know when something's wrong."
"I want to be believed the first time."

**QS214 recognises that these are
not complaints, they are truths.**





Shared Decision Making

Care **done to** people causes harm.
Care **done with** people builds trust.

**QS214 expects real conversations,
and decisions made together.**





The Reality for Many

Families become project managers.
People wait months for answers.
Support depends on where you live,
not what you need.

**QS214 exists because this is not
how care should be.**





Access to Treatment

The postcode lottery is not an inconvenience. **It is injustice.**
Where we live should not decide the access to care we get.

**QS214 calls for timely referrals,
specialist input and faster
diagnostics**





Coordination of Care

A named coordinator is not **“nice to have”**. It is the difference between **cop**ing and **collapsing**.

Joined up care reduces harm and lifts the burden families carry alone.

QS214 says people with rare diseases should not have to coordinate their own care.





Holistic Needs

Rare disease care is never just clinical. It affects mental health, identity, work, family life.

QS214 expects services to see the whole person, not just the rare condition.





The Heart of QS214

When lived experience leads, care becomes safer, kinder, fairer and more human.

QS214 expects services to see the whole person, not just the rare condition.





What Would Change If They Truly Listened?

**If QS214 were truly lived, not just
written, what would change for
people like us?**

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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**

Contact Us

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