

The Hidden Intersection of **LGBTQ+** Identity and Rare Disease





Double Invisibility

Many LGBTQ+ patients with rare diseases face assumptions about their identity, their relationships or their bodies.

This can delay diagnosis, distort care and make people feel unsafe sharing their full story.





Avoiding Care Because of Past Harm

Some LGBTQ+ patients avoid healthcare because of previous discrimination.

For rare disease communities, where early intervention matters, this can have serious consequences.





Why Inclusive PPIE Matters?

PPIE often relies on the “usual voices”.

But lived experience is shaped by identity.

If LGBTQ+ patients do not feel safe to participate, research and services miss vital insight.





Pride Is a Reminder

Pride began as a movement for voice and safety. Rare disease communities need those same protections.

Everyone deserves care where they can show up as their whole self.



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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