

Health equity for rare conditions



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Rare conditions are individually rare but collectively common, with **over 3.5 million people in the UK living with a rare condition. There are around 7,000 known conditions.**

7 in 10 rare conditions affect children. It is estimated that more than 50% of childhood deaths are associated with a rare condition.

In the UK, **1 in 17 people will be affected by a rare condition at some point in their life.** The experience of those living with these conditions is often defined by significant inequity, beginning with the 'diagnostic odyssey'. The most recent data on time-to-diagnosis for people with a rare condition shows that **1 in 4 in the UK waited at least 3 years between the first symptoms showing and receiving a confirmed diagnosis.** The same data indicates that for the vast majority (95%) of the 3 year wait, people were within the healthcare system i.e. they were actively seeking help from the health service. For many, a diagnosis remains entirely out of reach. Every year, **more than 6,000 children are born with a 'syndrome without a name' (SWAN),** meaning their condition is so rare that it does not yet have a name.

Inequity persists in the management and treatment of these conditions. **Only 1 in 20 rare conditions have an approved treatment or medicine to help.** Where there is an approved treatment, these are mostly for rare cancers.

People living with rare conditions often have complex health needs that require support across multiple health services, which means effective coordinated care is highly valued. However, **only 1 in 10 adults in the UK living with a rare condition have a care coordinator** to help organise different aspects of their care.

“ Equity for rare conditions means that no one is disadvantaged simply because their condition is unfamiliar, complex, or affects only a handful of people worldwide... Ultimately, equity looks like dignity, visibility, and meaningful inclusion, a system where being rare does not mean being forgotten. ”

- Person affected by neuroacanthocytosis (NA) syndromes: VPS13A disease (also known as chorea-acanthocytosis), XK disease (also known as McLeod syndrome)

About rare conditions

1 in 17 people will be affected by a rare condition at some point in their life

There are over 7,000 rare conditions, with new conditions regularly identified through scientific progress

1 in 4 in the UK waited at least 3 years between the first symptoms showing and receiving a confirmed diagnosis

7 in 10 rare conditions affect children

6,000 children are born with a 'syndrome without a name' (SWAN), meaning their condition is so rare that it does not yet have a name

What do we mean by health equity for rare conditions?

Health equity is a fundamental principle in public health that moves beyond the concept of uniform provision of health services to focus on fairness in health outcomes. The World Health Organisation defines health equity as ‘the absence of remediable differences among population groups’. It is important to distinguish this from health equality, which implies that every individual or group is given the exact same resources or opportunities. In contrast, equity acknowledges that various populations face distinct social, economic, and health barriers; therefore, resources must be distributed according to specific needs to ensure everyone can achieve their full health potential.

While rare is often used as a single label, there are more than 7,000 identified rare conditions. In the UK, a condition is considered rare if it affects fewer than 1 in 2,000 people. Some rare conditions affect thousands of people in the UK. Because of these numbers, they may be familiar to the public and the medical profession. At the other end of the spectrum many thousands of rare conditions affect fewer than 100 people in the country. Across rare conditions, scientific attention is not distributed evenly. Some conditions that have been known for decades may have established registries, natural history studies, and active clinical trials. For other conditions, there may be no active research at all. The level of support varies from rare condition to rare condition, with some having well established charities involved in providing support, research and campaigning, with others operating on a voluntary basis with limited resources and capacity. This doesn't mean some have it ‘easy’, the healthcare system creates different hurdles for different groups.

Achieving equity for the rare conditions community is therefore not about creating a new, separate definition of fairness. It is about ensuring the universal principle of care according to need is finally extended to the 1 in 17 people in the UK that will be affected by a rare condition at some point in their life. Their needs are currently overlooked by a healthcare system that systematically prioritises high-prevalence conditions at the expense of rare conditions. This requires a shift in how the NHS operates to ensure that the baseline of care for people with rare conditions is comparable to the safety, coordination, and speed experienced by those with common conditions.

“ We as parents are often ignored in the management of our child’s condition and belittled/blamed for decisions made by healthcare professionals. There is limited research into the condition. People do not understand the gravity of a life threatening, life long condition that is rare in comparison to a more known condition. ”
- Parent of a child affected by Glanzmann thrombasthenia



Learn more about the Equity for Rare campaign on Genetic Alliance UK's website

geneticalliance.org.uk/rdd26

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