

# UK Rare Diseases Framework and Action Plans

The UK Rare Diseases Framework was published in January 2021. This document outlines the governments' 4 priorities for improving care for people living with rare conditions to be implemented over 5 years (2021-2026).

Following engagement with various stakeholder groups including people living with a wide range of rare conditions and their families, the Framework identifies 4 priorities and 5 underpinning themes.



## What are rare conditions?

Learn more on [our factsheet](#)

### The 4 priorities are:



**1**

helping patients get a final diagnosis faster

**3**

better coordination of care

**2**

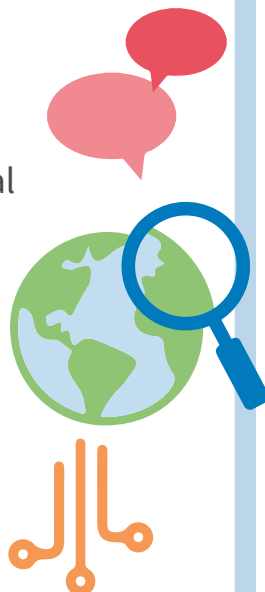
increasing awareness among healthcare professionals

**4**

improving access to specialist care, treatment and drugs

### The 5 underpinning themes are:

- patient voice
- national and international collaboration
- pioneering research
- digital, data and technology
- wider policy alignment



Each nation has published a Rare Disease Action Plan with specific measurable actions to implement the UK Rare Diseases Framework. They have also promised to review the plans annually.

[England](#) launched their action plan in February 2022 with updates in February 2023 and 2024. [Northern Ireland](#) launched their plan in March 2022. [Wales](#) launched in June 2022 with an update in January 2024. [Scotland](#) launched their action plan on 19 December 2022.