

Renewing the UK Rare Diseases Framework and Delivering a Modern Service Framework for Rare Conditions in England

Rare conditions affect more than 3.5 million people in the UK. The publication of the UK Rare Diseases Framework in 2021 was a significant milestone in addressing the needs of the rare community and the subsequent Rare Diseases Action Plans for England have sought to deliver improvements against four priorities:

1. Help patients get a final diagnosis faster
2. Increase awareness of rare diseases among healthcare professionals
3. Support better coordination of care
4. Improve access to specialist care, treatments and drugs

The UK Rare Diseases Framework is due to come to an end in January 2026. [The Specialised Healthcare Alliance and Genetic Alliance UK have published a report calling for a successor policy to the Framework](#) that is fully informed by the rare conditions community.

We are now urgently calling for the renewal of the UK Rare Diseases Framework, and for the development of a new Modern Service Framework for Rare Diseases in England.

The UK Government has now published the long awaited 10 Year Health Plan for England, setting out its vision for the future of the NHS in England over the next decade. While rare conditions do not feature prominently, this Plan is as important to the rare conditions community as the general public – so it is crucial that its ambitions are interpreted to account for the unique needs of people living with rare conditions.

The shift from hospital to community care, in the context of wider NHS England reform, could significantly impact the care people with rare conditions receive – though it is vital the NHS recognises that some specialised, complex care for rare conditions needs to remain hospital based.

The shift to preventing illness, not just treating it, is also highly relevant. Although many rare conditions aren't preventable, early detection through initiatives like newborn whole genome screening can lead to early treatment and better outcomes. The commitments on genomics are a promising step towards ending the diagnostic odyssey many people living with a rare condition face.

The rare conditions community experiences many of the major challenges identified in the 10 Year Health Plan, including fragmented and poorly coordinated care and delays to diagnosis. However, there are additional challenges for the rare community and unique opportunities to address them, including collaborative research and digital health solutions.

To ensure the NHS 10 Year Health Plan translates into tangible delivery for the rare community across England, a Modern Service Framework for Rare Conditions is needed. This Framework, aligned with models being developed in other therapy areas, would explicitly detail how the strategic priorities of the UK Rare Diseases Framework will be implemented and how the ambitions of the NHS 10 Year Health Plan for England will be realised for people affected by rare conditions.

When delivered alongside a renewed UK Rare Disease Framework that maintains vital four-nations collaboration and essential wider stakeholder involvement, a Modern Service Framework could deliver a cohesive national approach to the delivery of services for rare conditions in England.

The SHCA and Genetic Alliance UK's members are clear that the UK Rare Diseases Framework has been a vital vehicle for driving closer coordination between delivery partners within and across the four nations, and for creating momentum for new policies aimed at delivering advances in care and treatment for people living with rare conditions.

We are united in our call for a renewed, refreshed and re-energised UK Rare Diseases Framework. We believe that a Modern Service Framework for Rare Conditions is also necessary to ensure the rare conditions community in England benefits fully from the ambitions set out in the NHS 10 Year Health Plan.