

The Rt Hon Secretary of State for Health and Social Care
Department of Health and Social Care
39 Victoria Street
London
SW1H 0EU

Wednesday 14 May 2025

Urgent call to recognise rare conditions in the NHS 10-Year Health Plan for England and renew the UK Rare Diseases Framework

Dear Secretary of State,

We are writing to express serious concern on behalf of the 3.5 million people in the UK living with rare conditions, who we fear may fall through the cracks as the NHS 10-Year Health Plan for England is implemented.

In February 2025, the Department of Health and Social Care published '*Evidence on health inequities experienced by the rare disease community with regards to receipt of a diagnosis and access to health and social care services: a scoping review*'. The review finds consistent patterns of disadvantage, including delayed diagnosis, lack of clinician knowledge, inadequate care coordination, and limited access to both general and specialist services. These challenges are further compounded for women, ethnic minorities, people living in rural areas, and lower socioeconomically positioned groups.

While we are aware that individuals with rare conditions and the organisations that support them (including our own organisations) have contributed to the government's various consultations, it is highly likely that many respondents did not or could not always identify themselves as part of the community of people living with rare conditions. This lack of categorisation poses the serious risk that our community's needs may go unrecognised in the design and implementation of the NHS 10-Year Health Plan, even while they are among those most affected by gaps in the current system.

We recognise the 10-Year Health Plan's focus on its three major system shifts, and the necessary ambition to improve care experiences across the NHS. However, without explicit recognition of people living with rare conditions in the 10-Year Health Plan, we fear that this already marginalised group may

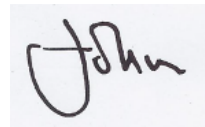
remain invisible, thereby perpetuating a hidden health challenge in the UK.

We urge you to deliver two vital actions: urgently renew the UK Rare Diseases Framework, which is essential for delivering specialist care to the 3.5 million people living with rare conditions, and ensure that the NHS-10 Year Health Plan explicitly references rare conditions to ensure the needs of our community are integrated into wider NHS system changes. These actions will create a comprehensive approach where the Framework's focused delivery is supported by system-wide awareness. We look forward to collaborating with your colleagues to deliver these actions

Yours sincerely,

A handwritten signature in black ink that reads "N. Meade". The signature is fluid and cursive, with the first name "N." and the last name "Meade" clearly distinguishable.

Nick Meade, Chief Executive,
Genetic Alliance UK

A handwritten signature in black ink that reads "John". The signature is written in a cursive style, with the first letter "J" being large and prominent.

Lord Sharkey, Chair,
Specialised Healthcare Alliance