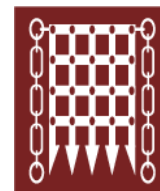


**Westminster Health Forum policy conference:
Priorities for rare disease diagnosis, care and treatment in England**

Timing: Morning, Thursday, 5th June 2025

*****Taking Place Online*****



**WESTMINSTER
HEALTH FORUM**

Draft agenda subject to change

- 8.30 Registration
- 9.00 **Chair's opening remarks**
Senior Parliamentarian
- 9.05 **Assessing the current landscape for rare diseases and priorities for patient engagement**
Senior commentator
Questions and comments from the floor
- 9.30 **Next steps for whole genome sequencing in newborn screening**
Professor Jim Bonham, President, International Society of Neonatal Screening
- 9.40 **Strategies for improving early detection, diagnosis and care coordination**
priorities from the England Rare Diseases Action Plan 2025 | delivering faster diagnostics and growing capacity | incentivising clinics for multi-system disorders | improving workforce awareness of rare diseases | equitable access to specialist care and treatment | innovative approaches to patient support | the future for specialised commissioning in NHS reform | priorities for the NHS Genomic Networks of Excellence | approaches to digitalising genomics
Senior representative, workforce
Senior representative, NHS
Senior representative, innovation
Senior representative, diagnostics
Senior representative, patient
- 10.10 Questions and comments from the floor
- 10.35 **Advancing development of targeted therapies and genetic medicine pathways for rare diseases**
Dr Ana Lisa Tavares, Clinical Lead, Rare Disease Research, Genomics England
Questions and comments from the floor
- 11.00 **Chair's closing remarks**
Senior Parliamentarian
- 11.05 Break
- 11.15 **Chair's opening remarks**
Senior Parliamentarian
- 11.20 **Priorities for Highly Specialised Technology evaluation and transparency**
Senior representative, guidance
Questions and comments from the floor
- 11.45 **The future for personalised treatments, innovative research, and clinical trials for rare diseases**
preparing the NHS to deliver personalised treatments | addressing potential treatment eligibility issues | advancing rare disease medicine development | improving recruitment to clinical trials | regulatory and operational challenges in delivering highly personalised treatments | opportunities for national and international collaboration | priorities for data sharing of real world evidence | centring patient experience and safety | future pathways for accelerated, safe, and approved therapies
Dr Simon Lande, CEO and Co-Founder, HealthLumen
Senior representative, industry
Senior representative, research
Senior representative, advocacy
Senior representative, legal
Questions and comments from the floor
- 12.30 **Next steps for rare diseases and delivering the England Rare Diseases Action Plan 2025**
Dr Kath Bainbridge, Head, Rare Diseases and Emerging Therapies, Department of Health and Social Care
Questions and comments from the floor
- 12.55 **Chair's and Westminster Health Forum closing remarks**
Senior Parliamentarian
Jessica Lear, Westminster Health Forum

This conference is supported by **HealthLumen**

