

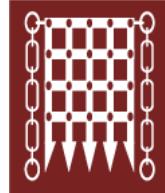
Westminster Health Forum policy conference

Next steps for rare diseases in England - new strategy, innovation, and patient access and experience

Timing: Morning, Thursday, 16th April 2026

Taking Place Online

Draft agenda subject to change



WESTMINSTER
HEALTH FORUM

8.30 Registration

9.00 **Chair's opening remarks**

Senior Parliamentarian

9.05 **Assessing progress so far in rare diseases and priorities for policy beyond the current framework**

Kath Bainbridge, Head, Rare Diseases and Emerging Therapies, Office for Life Sciences

Questions and comments from the floor

9.30 **The patient experience in rare diseases - improving care, access and outcomes**

Senior representative, patients

9.40 **Delivering improvements in diagnostics, care coordination and tackling inequalities**

next steps for implementing the England Rare Diseases Action Plan for 2026 | strategies for reducing diagnostic delays | addressing access inequalities for ethnic minorities and deprived communities | ensuring continuity during the UK Rare Diseases Framework extension | priorities for co-development of the successor framework with inclusive input | integrating genomic testing and hubs with routine care to reduce diagnostic delays | workforce capability in clinical genomics and cascade testing | specialised commissioning budgets and the role of ICSs | workforce planning and variation in expertise | training for digital tools, shared records and transparent reporting | the future for whole-genome new-born screening trials

Senior representative, education

Senior representative, NHS

Senior representative, research

Senior representative, diagnostics

10.00 Questions and comments from the floor

10.20 **Priorities for improving standards and quality of care in rare diseases**

Senior representative, guidelines

Questions and comments from the floor

10.45 **Chair's closing remarks**

Senior Parliamentarian

10.50 Break

11.00 **Chair's opening remarks**

Senior Parliamentarian

11.05 **Embedding genomic medicine in the NHS and opportunities for rare disease diagnosis and treatment**

Senior representative, genomics

Questions and comments from the floor

11.30 **'Progress of the Rare Therapies Launchpad - from research to treatment with iterative learning'**

Dan O'Connor, Director, Regulatory and Early Access Policy, Association of the British Pharmaceutical Industry

11.40 **Advancing research, innovation, trials and genomics in rare diseases**

priorities for new research platforms and data ecosystems in discovery | expanding clinical trial access, adaptive trial design and inclusivity for small populations | flexible evidence standards and n-of-1 approaches to support individualised therapies | supporting international collaboration and addressing funding gaps and investment in life sciences | tackling barriers to equity in research participation and innovation rollout | opportunities for the Launchpad to accelerate discovery and innovation | assessing progress on existing actions and new priorities for research, individualised therapies and clinical trials reform | data-sharing and real-world evidence | post-approval challenges and monitoring

Demetra Georgiou, Chair, British Society for Genetic Medicine; and Genomic Transformation Manager, Imperial College NHS Trust

Senior representative, research

Senior representative, data

Senior representative, industry

Senior representative, patients

12.05 Questions and comments from the floor

12.30 **Next steps for rare disease therapy regulatory frameworks**

Jon Beaman, Deputy Director, Innovative Medicines, Medicines and Healthcare products Regulatory Agency

Questions and comments from the floor

12.55 **Chair's and Westminster Health Forum closing remarks**

Senior Parliamentarian

Jessica Lear, Westminster Health Forum