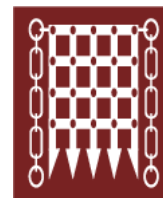


## Westminster Health Forum policy conference

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

Timing: Morning, Thursday, 16<sup>th</sup> April 2026

\*\*\*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 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