Westminster Health Forum policy conference
Next steps for rare diseases in England - new strategy, innovation, and patient access and experience
Timing: Morning, Wednesday 22nd April 2026
*****Taking Place Online*****

Draft agenda subject to change

8.30 Registration

9.00 **Chair's opening remarks**
Clive Jones MP , Officer, All-Party Parliamentary Group on Cancer; and Chair, All-Party Parliamentary Group on Breast Cancer

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**
Henry Poust, Secretariat, Specialised Healthcare Alliance

9.40 **Delivering improvements in diagnostics, care coordination and tackling inequalities**
next steps for implementing the England Rare Diseases Action Plan for 2026 | alignment with 10 Year Health Plan shifts | 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 | alignment with the National Cancer Plan for England and improving rare cancer outcomes | considerations for approaching rare
Dr Simon Briscoe, Senior Research Fellow, University of Exeter Medical School, University of Exeter
Professor Kate Tatton-Brown, Clinical Director and Head, National Genomics Education, NHS England; and Consultant Clinical Geneticist, St George's University Hospitals NHS Foundation Trust
Dr Isabelle Delon, Head, Rare Disease Service, Cambridge University Hospitals NHS Foundation Trust
Senior representative, NHS

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

10.40 **Chair's closing remarks**
Clive Jones MP , Officer, All-Party Parliamentary Group on Cancer; and Chair, All-Party Parliamentary Group on Breast Cancer

10.45 Break

10.55 **Chair's opening remarks**
Peter Dowd MP, Chair, All Party Parliamentary Group on Rare, Genetic and Undiagnosed Conditions

11.00 **Embedding genomic medicine in the NHS and opportunities for rare disease diagnosis and treatment**
Professor Sue Hill, Chief Scientific Officer, England, NHS England
Questions and comments from the floor

11.25 **Developing the Rare Disease Network of Excellence and pilot clinics for undiagnosed patients**
Professor Emma Baple, Professor, Genomic Medicine and Medical Director, South West Genomic Laboratory Hub and University of Exeter

11.35 **'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

11.45 **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 and ways forward for an operational framework | 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
Christie Brooks, Chief Data Officer, Arcturis Data
Professor Moin Saleem, Professor, Paediatric Renal Medicine and Director, Bristol Renal, University of Bristol
Demetra Georgiou, Chair, British Society for Genetic Medicine; and Genomic Transformation Manager, Imperial College NHS Trust
Samantha Barber, CEO, Gene People
Matt Bolz-Johnson, Public Affairs and Patient Advocacy Lead, Chiesi UK

12.10 Questions and comments from the floor

12.35 **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

13.00 **Chair's and Westminster Health Forum closing remarks**
Peter Dowd MP , Chair, All Party Parliamentary Group on Rare, Genetic and Undiagnosed Conditions
Jessica Lear, Westminster Health Forum