

UK RARE DISEASE POLICY BOARD

TERMS OF REFERENCE

Purpose

1. The UK Rare Diseases Policy Board is a UK-wide body with the purpose to facilitate discussion on the development of policies and strategies concerning research and development of new therapies and technologies for the treatment of rare diseases and their potential for patient benefit.
2. As well as supporting co-ordinated UK policy development and implementation, the Policy Board will consider how delivery of the UK Strategy for Rare Diseases might be enhanced and improved through the outputs of initiatives from across the broader genomics and rare diseases landscape. These include the 100,000 Genomes Project, developments in precision and personalised medicine and investment in research.
3. The Policy Board will work collaboratively with the UK Rare Diseases Forum to ensure that future policy development builds upon and supports implementation of the UK Strategy for Rare Diseases. This will be delivered in discussion with the Forum in considering policy direction and the inclusion of Forum members on Task and Finish groups that will consider specific aspects of policy development and delivery of the Strategy.

Terms of Reference

4. The UK Rare Diseases Policy Board has a remit to:
 - a) Facilitate the co-ordination of policy development and implementation across the UK on a wide range of issues pertinent to the delivery of the UK Strategy for Rare Diseases and future rare diseases policy.
 - b) Monitor advances in rare disease science and research, technology development, treatments and therapies and their potential to improve rare disease patient outcomes.
 - c) Engage with a wide range of experts and stakeholders on policy development and implementation through the use of Task and Finish groups where applicable.
 - d) Provide progress reports to Ministers on implementation of the UK Strategy for Rare Diseases.
5. The progress reports on implementation of the Strategy will be required in 2018 and 2020 and will cover the five themes in the report:
 - I. Empowering those affected by rare diseases
 - II. Identifying and preventing rare diseases
 - III. Diagnosis and early intervention
 - IV. Coordination of Care
 - V. The role of research

6. The Policy Board will align effectively with NHS England's Rare Diseases Advisory Group (RDAG) – and equivalent bodies in the devolved administrations - and will not duplicate the role of this group which acts in an advisory capacity to UK healthcare services on the co-ordination and development of specialised services and monitors implementation of the healthcare provision commitments in the UK Strategy.

Membership

The Chair

7. The UK Rare Diseases Policy Board will be co-chaired by the Deputy Chief Medical Officer (in their role as national rare diseases champion) and a patient representative. The patient representative co-chair will be nominated through the Policy Board for a two-year term. Terms can run consecutively with the agreement of the Board.

The Board

8. Membership will comprise of nominated persons from relevant bodies including:
 - The Department of Health
 - The Scottish Government
 - The Welsh Government
 - NHS Wales
 - The Northern Ireland Government
 - NHS England
 - NHS National Services Scotland
 - Health & Social Care Board Northern Ireland
 - Genomics England Ltd.
 - Public Health England
 - National Institute for Health and Care Excellence (NICE)
 - The Office of Life Sciences/Innovate UK
 - A patient representative nominated and agreed by the UK Rare Diseases Forum

The Secretariat

9. The Secretariat will be provided by the Department of Health.

Governance

10. The Policy Board is convened by the Department of Health with representation from all four countries of the UK.
11. The Co-Chairs are responsible for leading the Policy Board and facilitating the effective contribution of all members. The Co-Chairs will facilitate an effective working relationship with the UK Rare Diseases Forum to ensure that the views of its members are given due weight. The patient representative Chair will also be an ex-officio member of NHS England's Rare Diseases Advisory Group.
12. The Policy Board will have the scope to commission and convene 'Task and Finish' groups to take forward discrete projects which support delivery of

recommendations in the UK Strategy. Task and Finish groups may develop proposals and recommendations for the Policy Board to support evidenced based rare diseases policy development. Terms of Reference, membership and outcomes for individual Task and Finish groups will be agreed as and when they are commissioned.

13. Minutes of all meetings of the Policy Board will be publicly available through the rare diseases pages of the gov.uk website.
14. Communications between the Policy Board and the Forum will be through the Secretariat, except where it has been agreed that an individual member may act on the Policy Board's behalf.

Frequency of Meetings

15. It is intended that the Policy Board will meet as and when required at a time and date agreed by its membership. It will meet no more than 4 times per year. A record of members' attendance will be kept via the minutes.

Expenses

16. All attendees of the UK Rare Diseases Policy Board, who are not part of the civil or public service, will be entitled to claim reasonable travel expenses for attendance at Policy Board meetings, in line with existing DH travel and subsistence policy and rates.