

**UK Rare Diseases Framework Board terms of reference**

# Terms of reference

Following the publication of the UK Rare Diseases Framework, the Department of Health and Social Care (DHSC) is establishing the UK Rare Diseases Framework Board as a UK- wide body to oversee the delivery of the Framework, by providing co-ordination and alignment to rare disease policy across the four nations.

The purpose of the UK Rare Diseases Framework Board is to:

1. be a mechanism for collaborative work by harnessing the outputs from across the rare diseases landscape including developments in advanced medicines and investment in research
2. provide co-ordination and alignment during development of policies concerning therapeutic and diagnostic technologies for rare diseases, and their potential for patient benefit
3. support and co-ordinate delivery of the UK Rare Diseases Framework which will be carried out through nation-specific action plans
4. maintain awareness across all four nations of action plans and progress and inform of any challenges or new opportunities
5. make proposals for patient and public involvement, research activities, skills and training, industry involvement and on regulatory requirements, and guidance
6. work collaboratively with the UK Rare Diseases Forum on strategic issues

The UK Rare Diseases Framework Board will engage with the refreshed UK Rare Diseases Forum and with other relevant work across all four nations of the UK through existing mechanisms appropriate to the remit of the DHSC and members.

# Membership

## The Chair

The UK Rare Diseases Framework Board will be co-chaired by Dr Jeanelle de Gruchy, Deputy Chief Medical Officer of England and a rotating position between Professor Graham Ellis (DCMO Scotland), Professor Chris Jones (DCMO Wales) and Professor Ian Young (CSA Northern Ireland). The devolved nation co-chair will rotate each meeting.

## The Board

Core membership will comprise nominated persons from relevant bodies including:

**Table 1: Core membership of the Rare Diseases Framework Board**

|  |  |
| --- | --- |
| **Organisation or body** | **Role or suggested individuals** |
| DHSC | Policy lead |
| Northern Ireland Government | Policy lead |
| Welsh Government | Policy lead |
| Scottish Government | Policy lead |
| NHS England | Specialised Commissioning – delivery representative |
| NHS Scotland | Delivery representative |
| NHS Wales | Delivery representative |
| Health and Social Care in Northern Ireland | Delivery representative |
| Forum chair | Strategic advice |
| Delivery group/implementation board chairs | Policy advice |
| 3 patient representatives | Patient representatives |

The UK Rare Diseases Framework Board can invite non-members to attend meetings on an ad-hoc basis to provide relevant expertise where required.

## The Secretariat

The Secretariat will be provided by the Department of Health and Social Care.

# Governance

The UK Rare Diseases Framework Board is convened by the Department of Health and Social Care with representation from all four nations of the UK.

The Co-Chairs are responsible for leading the Board and facilitating the effective contribution of all members. The Co-Chairs will facilitate an effective working relationship with each nation’s respective implementation board (names will vary) and the UK Rare Diseases Forum to ensure a seamless flow of information, and that the views of members are given due weight.

The UK Rare Diseases Framework Board will have the scope to commission and convene ‘Task and Finish’ groups. The groups will take forward discrete projects on agreed subject areas requiring UK wide collaboration to support delivery of the priorities in the UK Rare Diseases Framework. Task and Finish groups may develop proposals and recommendations for endorsement by the Board which will be taken for consideration in the delivery or implementation groups in the respective nations. Task and finish groups will consider the health and social care structures within each of the devolved nations to support evidence-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.

Minutes of all meetings of the Board will be publicly available through links on the gov.uk website and DHSC Exchange.

Communications between the Board and the UK Rare Diseases Forum will be through the chair, except where it has been agreed that an individual member may act on the Board’s behalf.

# Frequency of meetings

It is intended that the Rare Diseases Framework Board will meet twice a year, with the potential of ad-hoc meetings between these sessions. In the first year of action plan development there will be additional meetings if required. A record of members’ attendance will be kept via the minutes.

# Expenses

All attendees of the UK Rare Diseases Rare Diseases Framework Board, who are not part of the civil or public service, will be entitled to claim reasonable travel expenses for

attendance at Framework Board meetings, in line with existing DHSC travel and subsistence policy and rates.

# Quorum and voting arrangements

Meetings will be quorate when one patient representative is present.

The Board has an oversight function and would not ordinarily make executive decisions. However, the co-chairs may exercise discretion as to whether a vote is required - in which case each member will have one equal vote.