



UK Rare Diseases Forum terms of reference

Terms of reference

The purpose of the UK Rare Disease Forum is to provide mechanisms for supporting meaningful engagement and collaboration between members of the rare disease community in the Forum, the UK Rare Disease Framework Board, and the Delivery Group/implementation boards for England and the devolved nations.

A user-friendly online knowledge and collaboration platform will be maintained to facilitate a live engagement medium for information sharing between the forum and Rare Disease Framework Board, and implementation/delivery board members. The secretariat will be responsible for organising ad-hoc Task and Finish Groups to support on specific issues, and liaising with the secretariats of the implementation/delivery groups and the Framework Board. The online platform will enable Forum members to engage with progress towards implementation of the Framework, share expertise and facilitate active discussion between members.

Under this model, the Forum will play a valuable role in engagement and in putting forward constructive and collective views that reflect experiences across the 4 nations.

The Forum will meet twice a year formally ahead of the UK Rare Diseases Framework Board, where developments and proposals will be discussed. The Forum will provide constructive and solution focussed feedback for the UK Rare Diseases Framework Board and implementation/delivery groups to consider.

Membership

The chair will be Alistair Kent who will coordinate views from the forum and will help in communicating updates both to and from the oversight boards. The Chair will represent the Forum on the UK Rare Diseases Framework Board.

The Forum will have an extended stakeholder membership to ensure that the stakeholder engagement covers the full range of activities needed to deliver the Framework, including for those rare diseases with a non-genetic cause. The membership will consist of clinical, operational, industry, research and policy stakeholders along with interested parties from the rare disease community with whom engagement is a priority. The Forum and its membership should complement existing stakeholder engagement mechanisms to prevent duplication.

The membership of the Forum will consist of senior representatives with experience in the rare diseases field including:

- patient organisations
- industry representatives
- research-active bodies
- clinical representatives
- digital and data representatives

The Secretariat

The Secretariat will be rotated between the devolved nations.

Governance

The Forum is held through DHSC Exchange by the Department of Health and Social Care with wide representation delivery and strategic partners as well as stakeholders who can provide expertise.

The Chair is responsible for leading the Rare Diseases Forum, facilitating the effective contribution of all members and holding delivery partners to account where appropriate.

Expenses

The forum will hold meetings online. Should in-person meetings be held, then all attendees of the UK Rare Disease Forum who are not part of the civil or public service are entitled to claim reasonable travel expense for attendance at Forum meetings, in line with existing DHSC policy on remuneration for Stakeholder Advisory Groups, which requires receipted proof of travel. In line with government policy, members are expected to demonstrate

value for money when booking train travel and that we will not normally reimburse for first class travel, except in special circumstances. The appropriate DHSC expenses forms will be made available to members.