

OPERATIONAL PRINCIPLES FOR THE UK RARE DISEASES POLICY BOARD TASK & FINISH GROUPS

1. The UK Rare Diseases Policy Board ('the 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. To inform the evidence base for policy development, the Board will commission task and finish groups to focus on specific issues pertinent to the UK Strategy for Rare Diseases and provide the Board with options and recommendations taking policy development forward. They will also provide the flexibility to commission discrete and clearly defined projects to support further implementation of the UK Strategy. Membership of task and finish groups will be drawn from a wide range of experts and stakeholders to deliver the specialist knowledge, skills and expertise required to progress a particular issue.
3. Subjects for task and finish groups can be proposed by others, such as the UK Rare Diseases Forum, but their establishment must be endorsed by the Board. Endorsement will only be given if adequate resources to run a task and finish group are identified and agreed.
4. Task and finish groups will be subject to the following operating principles:
 - All Task and Finish groups must include patient representation.
 - Subjects for task and finish groups must support either the further implementation of the UK Strategy for Rare Diseases or an issue related to science, research or healthcare in the field of rare diseases.
 - All task and finish groups must have a nominated a Chair (this could be a patient representative, if appropriate).
 - Each task and finish group must have Terms of Reference which will include clear deliverables/outputs with timescales.
 - All task and finish groups will have a clear start and end date with a time line that should ideally not be longer than 6 months. Exceptionally, for example where the issue under consideration is complex or specific expertise needs to be commissioned, the duration may be extended beyond 6 months but not longer than 18 months.
 - All task and finish groups will generally conduct their business electronically unless there is a clear need for physical meetings to be convened.
 - At the conclusion of their work, task and finish groups must provide a report back to the Board summarising its findings, suggesting possible actions and recommending how to demonstrate delivery and improvement.