



England Rare Diseases Action Plans Patient Advisory Group Terms of Reference

Purpose of the Group

1. The England Rare Disease Action Plans Patient Advisory Group will amplify the voice of people with lived experience of rare conditions in shaping England's 2024 Rare Diseases Action Plan.
2. DHSC officials will consider comments and feedback that arise from the Group and take them forward to the England Rare Diseases Framework Delivery Group. DHSC officials will report back to the Group detailing how their comments were considered.
3. The Group will not be responsible for the development of, or sign-off on, the England Rare Diseases 2024 Action Plan (this is the responsibility of the England Rare Diseases Framework Delivery Group), nor will members be expected to endorse the Action Plan at publication.

Meetings

4. Meetings will be up to two hours long. Two meetings will be held during the drafting period in Autumn 2023 and a third meeting will be held following publication in March 2024 to seek further reflections and help define priorities for the year ahead.
5. Meetings of this Group should not occur on the same day as meetings of Genetic Alliance UK's [Patient Empowerment Group](#).
6. The continuation, function and operations of the Group will be reviewed by DHSC, Genetic Alliance UK staff and the members of this Group following the publication of the 2024 Action Plan.
7. Papers to be discussed at the meetings will be shared with the Group a minimum of three working days before the meeting to allow for reading and consideration.

Membership

8. Membership of the Group will consist of people living with a rare condition, those who care for them, or those who represent charitable or advocacy groups for people living with a rare condition and those caring for them. Officials from DHSC will attend to present and join discussions.
9. There should be between 20-30 members to ensure a diversity of views but a chance for all to contribute meaningfully to an inclusive discussion, with a minimum of 10 members required to reach quorum.
10. Membership will consist of current members from Genetic Alliance UK's [Patient Empowerment Group](#) with wider members recruited by Genetic Alliance UK to ensure representation is as broad and diverse as possible.
11. Members may seek feedback from non-Group members of the wider community, but any meeting papers circulated must remain confidential between members of the Group.

Secretariat

12. Genetic Alliance UK will provide the secretariat for the Group, including developing the membership list, scheduling, hosting, chairing and minuting meetings.

13. DHSC will work closely with Genetic Alliance UK to ensure that the membership list, agenda, meeting times and outputs are well aligned with the policy development process.
14. DHSC will be responsible for the provision of steer on the topics for meetings, and the provision of drafts of policy documents in advance of meetings. The papers may include unpublished drafts of national policy documents and as such would need to be treated as confidential to the group.

Governance

15. The group will be chaired by Genetic Alliance UK. The Chair is responsible for leading the discussion, facilitating the effective contribution of all members.

Expenses

16. DHSC will provide remuneration to cover Genetic Alliance UK's costs in providing the secretariat as agreed. This covers hosting and chairing meetings, and providing reports of the meetings.
17. Meetings will be held virtually.