



Department
of Health &
Social Care

UK Rare Diseases Delivery Group for England

Patient Representative Recruitment Pack

May 2021

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INFORMATION FOR APPLICANTS

How to apply

Thank you for your interest in applying to become a patient representative on the UK Rare Diseases Delivery Group for England.

As you will know, the UK Rare Diseases Framework was published in January, setting out a strategic national vision for improving the lives of people living with rare diseases. Implementation of the Framework will be achieved by each nation of the UK producing their own specific, measurable Action Plan, detailing how the priorities of the Framework will be met.

We view patient involvement as a crucial part of this implementation phase, and for this reason we aim to recruit two patient representatives to serve on the Delivery Group for England, which will develop and monitor implementation of the England Action Plan.

On the following pages you will find the information you need to complete your application.

1. Role description
2. Supporting statement form (please complete and return)
3. Draft terms of reference for the UK Rare Diseases Delivery Group for England (will be ratified at the first meeting)

Please submit your application **by 2 June 2021 to:** Lauren Watson, Rare Diseases Policy Lead, at: lauren.watson@dhsc.gov.uk

Any queries relating to your application may also be directed to this address.

What happens next?

After the closing date we will compile a shortlist of potential candidates, by assessing your supporting statement against the contents of the role description. Shortlisted candidates may be invited to an informal interview (via telephone or video call). This will give you the opportunity to tell us what experience and qualities you would bring to the role. You will also be able to ask us any questions that you may have.

Should you be selected for interview, we will contact you in advance to arrange a time and date. We want you to give the best interview experience we can, so please let us know before the interview if you have any particular requirements or access needs.

Candidate feedback

We aim to inform all candidates of the outcome of their application within two weeks of the closing date.

We look forward to receiving your application.

ROLE DESCRIPTION

Background

On 9th January 2021, the UK Government published the new [UK Rare Diseases Framework](#), which provides the high-level direction for rare diseases over the next 5 years, and outlines a coherent, national vision for how the UK will improve the lives of those living with rare diseases. The Framework lists four key priorities for moving forward:

- helping patients get a final diagnosis faster;
- increasing awareness of rare diseases among healthcare professionals;
- better coordination of care; and
- improving access to specialist care, treatment and drugs.

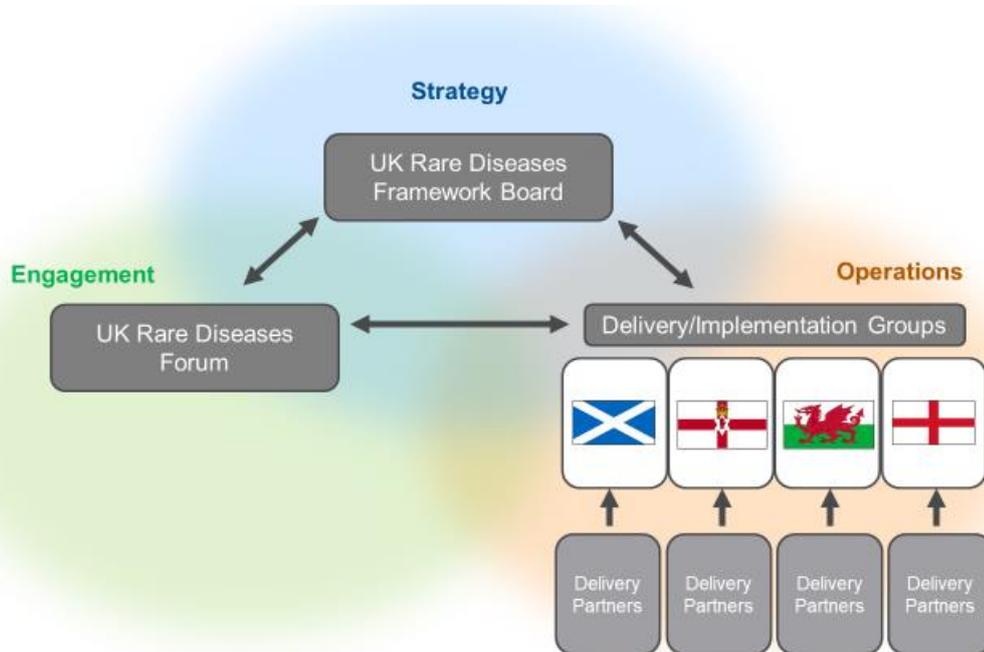
The Framework is supported through ongoing work in 5 underpinning themes:

- using digital tools, data, and technology to improve efficiency, the patient experience, and research;
- maximising national and international collaboration with the rare disease community to drive better outcomes;
- ensuring alignment with wider policy so that issues affecting the rare disease community are recognised across government;
- pioneering research, so that we can harness the potential of cutting-edge science and translate outcomes into frontline clinical care; and
- putting the patient voice at the centre of decision making.

The implementation of the Framework will be achieved by each nation of the UK producing their own Action Plan, detailing how the priorities of the Framework will be met, and taking into account their health systems and populations. Delivering the Framework as a UK-wide strategy will require coordination and oversight by the four nations and key officials, and will be achieved through the creation of three new governance structures:

- The UK Rare Diseases Framework Board, providing high level alignment and coordination of rare disease policy and action plans across the four nations.

- The Rare Diseases Delivery Group for England, providing specific oversight and coordination of England's action plan (similar delivery/implementation boards will be created for each of the four nations), and
- The UK Rare Diseases Forum, providing a live engagement platform for a wide range of stakeholders for advice and input.



Role description

To ensure that patients are involved in the development and delivery of our Action Plan for England, we are looking for two patient representatives to join as members of the **UK Rare Diseases Delivery Group for England**.

The role will involve:

- Preparing for meetings by reading and assessing meeting papers
- Attending Delivery Group meetings (see time commitment below for more information) and taking part in discussions as a representative of the broader rare disease patient community
- Providing feedback on documents between meetings, where appropriate

- Providing a link between the Delivery Group and the rare disease community, by providing feedback to the community, and raising community concerns at the Delivery Group where appropriate

Time Commitment and Expenses

The UK Rare Disease Delivery Group for England will meet quarterly – usually in January, April, July and October. However, in 2021, the Group will meet every six weeks in order to deliver the Action Plan for England. Meetings are expected to last approximately 1.5 hours, and will be conducted virtually (via Microsoft Teams) for the foreseeable future. Should in-person meetings resume, members can continue to join virtually where appropriate. Patient representatives will commit to serving on the Delivery Group for two years, followed by a period of handover to their successors.

Patient representatives will be entitled to claim reasonable travel expenses for attendance at in-person Group meetings, in line with Department of Health & Social Care rates

Who are we looking for?

We are looking for committed individuals who have experience, insight and interest that can help to facilitate the delivery of the UK Rare Disease Framework.

The ideal candidate should:

- Be a rare disease patient, family member or carer
- Have experience of advocating on behalf of rare disease patients and their families at board level (or in a similar environment)
- Be able to articulate the needs, experiences, concerns and aspirations of rare disease patients and their families
- Possess well-developed communication, influencing and negotiating skills.

We are particularly keen to ensure that patient representatives serving on the Delivery Group represent the interests of the diverse rare disease community.

Question 2

Please provide ONE example of when you have demonstrated the ability to reflect a broad range of patient perspectives in addition to your own personal experience.

Please use no more than 250 words.

Question 3

If applicable, please list any current or previous employment or voluntary positions that you feel are relevant to the role (including board membership and/or patient advocacy experience).

ENGLAND RARE DISEASES FRAMEWORK DELIVERY GROUP DRAFT TERMS OF REFERENCE

Terms of Reference

1. The purpose of the England Rare Diseases Framework Delivery Group is to develop, agree and monitor action plans and dependencies for England. Membership of the Group will primarily consist of the key delivery partners and the rare diseases policy team in DHSC.
2. The Delivery Group will:
 - a. Facilitate the development of UK Rare Disease Framework action plan for England. Three or four actions will be set against each Framework priority area, with a clear action owner and an agreed metric for each. These deliverables will also require the owners to provide evidence of work in the underpinning themes of the Framework.
 - b. Agree and monitor key deliverables and dependencies
 - c. Establish a risk and issue register, and monitor the impact of mitigation strategies
 - d. Identify critical implementation issues and support the policy team as necessary in formulating options for Ministers.
 - e. Report to the UK Rare Diseases Framework Board for discussion and advice.
 - f. Develop a communications strategy in partnership with key stakeholders
 - g. Consider any additional funding requirements for actions that stretch beyond business as usual.
 - h. Work collaboratively with the Rare Diseases Forum on operational issues.

Escalate draft action plans to the UK Rare Disease Framework Board for approval.

Membership

The Chair

3. The England Rare Diseases Delivery Group will be chaired by the director of Science Research and Evidence Directorate in DHSC. The vice chair is Head of the Genomic Science and Emerging Technologies Branch in the event of the chair's absence.
4. Membership will comprise of delivery partners who are taking forward actions, and relevant stakeholders.
5. Members of the England Rare Diseases Delivery Group should nominate one representative who holds a senior position able to make operational decisions. This is our current view of who will sit on the delivery group, but this will depend on who is specifically commissioned for actions.

Table 3: Examples of delivery partners who might make up the England delivery group (not exhaustive).

| Organisation/body | Priorities or themes to lead on |
|---|---|
| DHSC | Policy team leading on the Framework |
| NHS England | All |
| Public Health England (NCARDRS) | Coordination of care, digital data and technology |
| National Institute for Health and Care Excellence (NICE) | Access to treatment |
| Office for Life Sciences | Policy advice |
| Health Education England (HEE) | Awareness |
| Medical Research Council (MRC) | Pioneering research |
| Newborn Screening Team (DHSC) | Faster Diagnosis |
| NIHR | Pioneering research |
| NHS Digital/NHS-X | Coordination of care, digital data and technology |
| 1/2x Patient representatives | Patient voice |

The Secretariat

6. The Secretariat is provided by the Department of Health & Social Care.

Governance

7. The Delivery Group is convened by the Department of Health & Social Care with representation from all delivery partners in England who own and deliver actions to meet the priorities of the Framework.
8. The Chair is responsible for leading the England Rare Diseases Delivery Group, facilitating the effective contribution of all members and holding delivery partners to account where appropriate.

Frequency of Meetings

9. The England Rare Diseases Delivery Group will meet quarterly. Substitutes will only be permitted by agreement with the secretariat. Videoconferencing and teleconferencing facilities can be provided. A record of members' attendance will be kept via minutes.

Expenses

10. All attendees of the England Rare Diseases Delivery Group, who are not part of the civil or public service, are entitled to claim reasonable travel expenses for attendance at Group meetings, in line with existing Department of Health & Social Care travel and subsistence policy and rates.

Quorum and voting arrangements

11. Meetings will be quorate when one patient representative is present.
12. The Board has an advisory function, and does not 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.