



Department  
of Health &  
Social Care

# UK Rare Diseases Framework Board

## 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 Framework Board.

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 one patient representative, to serve alongside Genetic Alliance UK on the UK Rare Diseases Framework Board, which will provide oversight and coordination of rare disease policy and action plans across the four UK nations.

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 Framework Board (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](mailto: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:

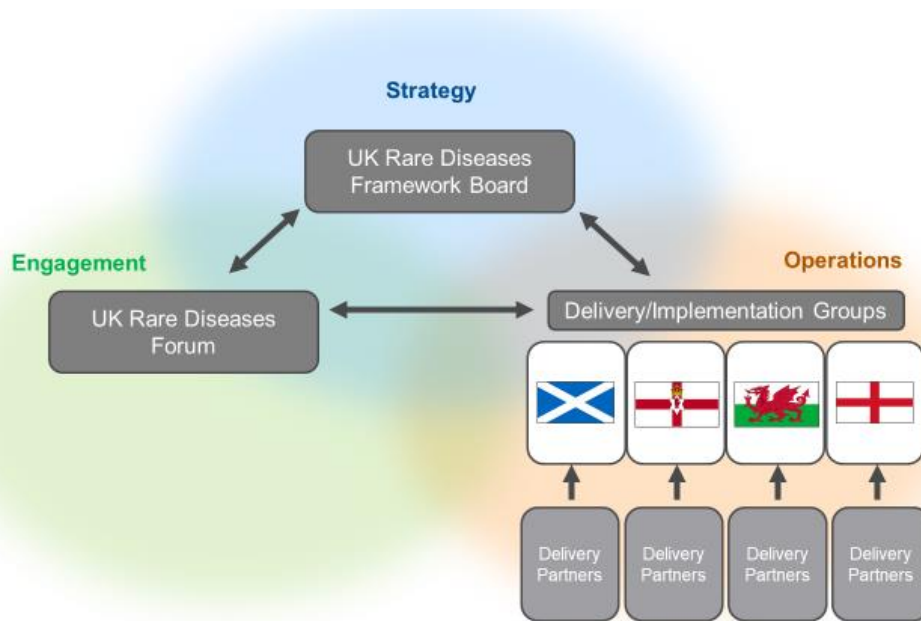
- helping patients get a final diagnosis faster;
- increasing awareness of rare diseases among healthcare professionals;
- better coordination of care; and
- improving access to specialist care, treatment and drugs.

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 4 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 the Action Plans, we are looking for one patient representative to join Genetic Alliance UK as a member of the **UK Rare Diseases Framework Board**.

The role will involve:

- Preparing for meetings by reading and assessing meeting papers
- Attending 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

- 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 Framework Board will meet twice a year – in July and November 2021, and May and November in subsequent years. 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 Board 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 UK Rare Diseases Framework Board represent the interests of the diverse rare disease community.

## SUPPORTING STATEMENT APPLICATION FORM

To help you to give the best possible statement, please bear in mind the following:

- Read the Role Description carefully so that you are clear about what the role involves and what we are looking for.
- Use your supporting statement to tell us why you are a good fit for the role
- Keep your supporting statement clear and concise

**Please note:** if you are unable to insert an electronic signature in the form overleaf, just leave it blank.

When you have completed your Supporting Statement please return it to: [lauren.watson@dhsc.gov.uk](mailto:lauren.watson@dhsc.gov.uk)

Name: \_\_\_\_\_

Email address: \_\_\_\_\_

Telephone number: \_\_\_\_\_

Signature: \_\_\_\_\_

Date: \_\_\_\_\_

### Question 1

Why are you applying for this role and what background, qualities, knowledge and insight will you bring? **Please use no more than 500 words.**



**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).

## UK RARE DISEASES FRAMEWORK BOARD DRAFT TERMS OF REFERENCE

### Terms of Reference

1. 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 coordination and alignment to rare disease policy across the four nations.
2. The purpose of the UK Rare Diseases Framework Board is to:
  - a. 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.
  - b. Provide coordination and alignment during development of policies concerning therapeutic and diagnostic technologies for rare diseases, and their potential for patient benefit.
  - c. Support and co-ordinate delivery of the UK Rare Diseases Framework which will be carried out through nation-specific action plans.
  - d. Maintain awareness across all four nations of action plans and progress and inform of any challenges or new opportunities.
  - e. Make proposals for patient and public involvement, research activities, skills and training, industry involvement and on regulatory requirements, and guidance.
  - f. Work collaboratively with the UK Rare Diseases Forum on strategic issues.
3. 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

4. The UK Rare Diseases Framework Board will be co-chaired by Chief Medical Officer of England (Professor Chris Whitty) alongside a rotating position for an official of equivalent seniority from each of the devolved nations. The devolved nation co-chair will rotate each meeting.

### The Board

5. Core membership will comprise nominated persons from relevant bodies including:

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

<b>Organisation/body</b>	<b>Role/suggested individuals</b>
<b>DHSC</b>	Policy lead
<b>Northern Ireland Government</b>	Policy lead
<b>Welsh Government</b>	Policy lead
<b>Scottish Government</b>	Policy lead
<b>NHS England</b>	Specialised Commissioning – delivery representative.
<b>NHS Scotland</b>	Delivery representative.
<b>NHS Wales</b>	Delivery representative.
<b>Health and Social Care in Northern Ireland</b>	Delivery representative.
<b>Forum chair</b>	Strategic advice
<b>Delivery group/implementation board chairs</b>	Policy advice
<b>2x Patient representatives</b>	Patient representatives

6. 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

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

## Governance

8. 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.

9. 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.
10. 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/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.
11. Minutes of all meetings of the Board will be publicly available through links on the gov.uk website and DHSC Exchange.
12. 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**

13. 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**

14. 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**

15. Meetings will be quorate when one patient representative is present.

16. 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.