

Patient  
Representative to  
the NHR Steering  
Group  
Application information pack

NHS England and NHS Improvement



## Contents

1. Introduction .....	2
2. How to apply .....	2
3. Diversity and equality of opportunity .....	2
4. Once we receive your application .....	2
5. Background, context and aims of the programme .....	3
6. Role of the group .....	4
7. Importance of Patient Representatives .....	4
8. What is the role of Patient Representatives on the group .....	5
9. Skills and experience are required for this role .....	5
10. Time commitment .....	5
11. Support for Patient Representatives .....	6

# Application information pack for NHR (National Haemoglobinopathy Registry) Steering Group - Patient Representative

## 1. Introduction

Thank you for your interest in becoming a Patient Representative on the NHR (National Haemoglobinopathy Registry) Steering Committee.

The NHR (National Haemoglobinopathy Registry) is committed to ensuring that patient voices are at the centre of shaping our activities. Patients' views should inform service development, improvement and research.

Please read this application information pack before completing the application form for this role, to ensure you fully understand the application process, and to determine whether you have the skills and time to become a Patient Representative.

Please note that correspondence will be primarily via email, unless otherwise requested. If you do not have access to email and would like to be contacted via telephone or post, please state this on your application form.

## 2. How to apply

Please complete and return the following accompanying documents:

- Application Form
- Equal Opportunity Monitoring Form

You can either return these documents by email;

[england.npoc-bloodandinfection@nhs.net](mailto:england.npoc-bloodandinfection@nhs.net)

If you would like support to enable you to apply for this role, and/or information in another format please contact the above email address.

We will rely on the information you provide in the application form to assess whether you have the skills and experience required for this role.

## 3. Diversity and equality of opportunity

NHS England and members of the NHR values and promotes diversity and is committed to equality of opportunity for all. To help us understand if we are achieving this, we ask you to fill out an Equal Opportunity Monitoring Form as part of the application process.

Please let us know if you have support needs so that we can understand how we can support you to participate fully.

## 4. Once we receive your application

The steps will be as follows:

i) Applications will be shortlisted by a panel, including members drawn from the Steering Committee of the NHR. We are looking for approximately four patient representatives to be members of the steering group.

- ii) Applications will be assessed against the skills and experience required, outlined in section nine (below). Selection will be made on the basis of the content of the application form.
- iii) Interviews will take place via MS teams/teleconference facilities. You do not need to know how to use these now in order to apply.
- iv) Please note that two references will be taken up for successful applicants before involvement can commence.
- v) Patient Representative roles do not require DBS clearance.
- vi) All applications will receive a successful or unsuccessful notification. The successful notifications will include information about next steps.

As per our Patient and Public Voice ([PPV Partners Policy](#)), NHS England has categorised the different participation opportunities we offer, and different ways in which we work with PPV Partners, into four different types of roles. These roles have been linked to the categories of financial support, as follows:

For the NHR steering group [Role three](#) is applicable; Role 3: PPV Partner is a member of regular working group meetings.

If you have any queries about the application process or would like an informal discussion about the opportunity – please contact either Dr Noémi Roy Clinical lead or Sharon Hodgson NHS England Programme of Care manager at the below email address:

[england-npoc-bloodandinfection@nhs.net](mailto:england-npoc-bloodandinfection@nhs.net)

## 5. Background, context and aims of the programme

The National Haemoglobinopathy Registry is a clinical registry which holds data on all patients in England with an inherited anaemia. This covers people living with Sickle Cell Disease, Thalassaemia, Diamond Blackfan Anaemia, Sideroblastic Anaemia, Congenital Dyserythropoietic Anaemia, Pyruvate Kinase deficiency and other rare types of anaemias.

The Registry holds this data for clinical safety (e.g. if a patient attends a hospital where they are not known; their data would be available to the medical teams at that hospital) and for clinical commissioning reasons (allocating funding to each hospital in accordance to the number and severity of the patients in that region). This part of the Registry has been approved for clinical use, meaning that patient consent is not necessary.

The second part of the Registry contains clinical data which is not needed for direct clinical care or commissioning purposes. However, it is data that is important for research purposes, to gather data that will help determine which treatments carry better outcomes, or whether any complications are more common in certain patients. This data will require patient consent. Access to the non-identifiable data for research purposes will be regulated by a Data Access Committee which will have Patient Representatives, with any final approval being sought from NHS England/Improvement.

The purpose of the Steering group will be to look to scope and develop a scheme of work for the Clinical Reference Group (CRG) which outlines on any future development the NHR for consideration. This should meet the requirements for Regional and National commissioners within NHS England and its wider stakeholders. The patient

voice in this work is imperative.

As part of the governance process all proposals will require approval by the Programme of Care steering group and NHS England senior management teams.

## 6. Role of the steering group

The role of the NHR Steering Group members, as a multi stakeholder group of representatives from clinical and managerial backgrounds, will have the patient and public voice at the centre of the group, the group will provide leadership over four aspects:

- a. Ensure that the registry provides the data required for existing and any future data returns to NHS England/Improvement, e.g. specialised services quality dashboards (SSQD).
- b. Collect data on monitoring, complications and therapies which informs NHS commissioners on how best to support commissioning decisions for the delivery of high quality Haemoglobinopathy services (e.g. iron chelation therapy, blood transfusion using automated apheresis)
- c. Support long term outcome data on patients who are receiving therapeutic interventions commissioned by the NHS to assess the effectiveness of therapy being commissioned and meet regulatory authorities' requirements.
- d. Enable and support National Haemoglobinopathy Panel (NHP) functioning as an MDT discussion outcome repository.

## 7. What is the role of Patient Representatives on the group?

Patient representation will bring important views, perspective and challenge into the NHR Steering group. This role is essential in championing the service user, patient and/or carer/family viewpoint, ensuring that their needs are met through the outcomes of the programme.

The role of the Patient Representative is to:

Ensure that the committee/group considers and prioritises the service user, patient, carer and family perspective, this will then inform NHS England/Improvement commissioning decisions.

- Champion the diversity of patient representative views, and not just to represent their own experience.
- Provide 'critical friend' challenge into the group.
- Champion and advocate for increasing patient and public awareness of the programme's outcomes and achievements.
- Review and comment on documentation, research and data requests and publications from the registry such as the annual report.
- Provide patient led views on work programme development / workstreams.
- Provide advice on any patient focussed NHR developments.
- Comply with the NHS England Standards of Conduct, respecting the confidential nature of discussions when it is made clear by the Chair that this is a requirement.

## 8. Skills and experience required for this role

- Provide an objective voice with the ability where necessary, to constructively challenge, influence and help the Steering group develop strategies in respect of its work programme.
- Bring independent judgement and experience from a patient and citizen perspective.
- High level of organisation, self-motivation and drive for performance.
- Personal integrity and commitment to openness, inclusiveness and high standards.
- Ability to work effectively, constructively with senior multi stakeholder colleagues.
- Prepared to contribute actively to the discussions and work of the NHR.
- Ability to understand and evaluate a range of information and evidence.
- Ability to display sound judgement and objectivity.
- Have an awareness of, and commitment to, equality and diversity.
- Understand the need for confidentiality.
- A commitment to the 'seven principles of public life' (sometimes known as the 'Nolan Principles': selflessness, integrity, objectivity, accountability, openness, honesty, leadership).

## 9. Time commitment

- Initially there will be trial period of three months. Membership of the group is then for a further nine months; ongoing participation will be reviewed on an annual basis as per of the Terms of Reference. Membership of the stakeholders will be for a maximum of three years.
- Each patient representative will play a critical role in supporting and advising NHS England on the development of any patient focussed workstreams.
- There will be at least three/four patient members on the steering group.
- The aim of all the work is to ensure as many patients and groups are able to engage, inform and input into the work, as such we will look to use technologies to engage with patients and their families to ensure all voices are heard.
- There may be further additional bespoke patient focussed events that will require support in the development and involvement on an as and when basis.
- Meetings will all be held through tele/videoconferencing facilities whenever possible.
- Prospective applicants should also be aware that some of the documents will be complex and confidential and will be subject to NHS England governance, they will also require reading time prior to the meetings.

## 10. Support for Patient Representatives

The NHR (National Haemoglobinopathy Registry) is committed to fostering meaningful patient engagement. As such, the NHR will hold an introductory meeting with all new Patient Representatives with the following aims:

- a) Brief training on patient engagement.
- b) Development of a patient engagement charter- this will set out the principles by which both the patient representatives and the rest of the steering committee will engage (e.g. use of lay language).
- c) Development of the patient representatives' goals and aspirations.
- d) Provision of an independent patient engagement mentor.

## 11. Governance

The NHR steering group are not decision-making body. Overall governance for the group sits with NHS England, with scheme of work being overseen by the Clinical Reference Group and Blood and Infection Programme of Care

