

Patient Representative Role Description

North East and Yorkshire Sickle Cell HCC Board

Title: Patient Representative

Patient engagement: Role that does not attract payment.

Time Commitment: Monthly meetings Online (Teams). 1 hour duration, time to read papers connected to meetings, opportunities to attend working groups and other meetings, and provide feedback on documents produced by the HCC.

Venue: Microsoft Teams (virtual)

Role Duration: 2 years (this will offer other patients a chance to represent, however, there may be opportunity for extension)

The North East and Yorkshire Haemoglobinopathy Coordinating Centre (N E & Y HCC) for Sickle Cell aims to provide high-standard and equal care across the region. We value the role of patient representatives who are able to bring a unique perspective to the Board. As you are an expert by experience, we believe your experiences can be utilised to engage in meaningful discussions to shape the services and systems which provide your healthcare.

Patient Representative Roles and Responsibilities:

The role of patient representatives is to ensure that care is patient-centred with the views and ideas of patients being heard. Patient representatives are therefore expected to contribute to decision making.

Patient representatives will:

- provide a well-rounded perspective of the challenges, successes and areas of improvement required in the care of Sickle Cell.
- commit to attending as many Board meetings as they are able to
- collaborate with Board members through constructive discussion.
- provide feedback on documents produced by the HCC.
- to help people have a voice.
- to act in a courteous manner
- comply with the relevant policies and practices of the NHS
- recognise that you represent the NE&Y HCC panel and therefore need to always act in an appropriate manner when attending meetings
- notify the NE&Y HCC panel administrator if you are unable to attend a meeting

- to commit to the time period of 12 months and let us know as soon as if there is a problem with this

Commitments of Other Business Meeting Members to the Patient Representatives:

- to welcome open, honest and constructive feedback from the patient representative
- consider patient representatives as full members of the Board
- provide you with clear information about your role within the NE&Y HCC Service and carer panel
- always treat you respectfully and professionally
- reimburse out of pocket expenses if there are receipts or evidence of expenditure
- communicate with you regularly and keep you informed of any changes relevant to your role