

National Haemoglobinopathy Registry Steering Group Terms of Reference 20/21

Aims of the Steering committee

The aims of the steering group are to:

- Oversee governance and development of the registry
- Work with NHS England/Improvement to ensure that the registry is developed in line with the requirements of NHS England/Improvement
- Work with the provider of the NHR to ensure benefits are realised from the system
- Review and authorise requests for change of data fields from NHS organisation's that require data from the NHR for commissioning purposes and for the assessment of quality of services.
- Review and discuss any adhoc engagement required by provider agency in order to ensure all decisions have final review and oversight from the steering group with final sign off be sought from the Haemoglobinopathy CRG/PoC Board dependent on requirement.
- Scope, develop a submit workplan for developments for the NHR to the CRG/PoC.
- Work with NHSE and the provider of the NHR to develop the direction of travel for future development of the registry in respect to new dashboards, key performance indicators – this should be integral to the workplan.
- Support development and updates facilitate patient engagement and patient reported outcomes
- Review data from the registry and write the annual report produced from this data
- Review all data requests and research proposals and make recommendations regarding feasibility to the UKFHD and NHS England/Improvement.
- The group will make recommendations on approval of data requests to NHS England/Improvement – upon the review this will be sent to NHS England/Improvement for final approval.
- The steering group is not a decision-making body and as such, does not have the governance to make any final decisions on data within the NHR – this will require NHSE/I oversight, scrutiny and approval.

Membership

The chair is appointed through NHSE/I in collaboration with UKFHD. This post will be for 3 years on each appointment.

The membership will be nominated from the relevant groups

The group comprises the following:

- Provider agency representative
- HCC representatives x 10
- Data manager group x1 representative at any meeting
- Patient representatives x 3
- NHSBT clinical representative
- Rare Anaemia representative
- Newborn outcomes Programme representative
- Lead commissioner or representative – National
- NHS England/Improvement – Information Governance/Data controller
- NHP membership

Chair: The current Chair will continue for the financial year 2020/2021 and will be re-selected at this point.

Co-Chair – NHS England/Improvement – PoC manager or NHSE data controller

Accountability and Reporting

NHS England are the data owners for the NHR, and any data related issues should be reported through appropriate NHS England routes. The steering group will also report to the Clinical reference group (CRG) for Haemoglobinopathies for data related issues, the UKFHD for oversight and the NHP for issues related to the national MDT.

Frequency of meetings

Meetings will be held four times per annum, initial meetings may be called on an as and when basis when required. These will be by teleconferencing and video conferencing facilities. Quorate will be

- a. NHR chair or co-chair
- b. 4 representatives from HCCs
- c. Provider agency representative
- d. Patient representative
- e. Commissioning representative x 1

Additionally, ad hoc engagement will run throughout the year. The provider agency may contact the steering group members in between meetings to:

- ask for feedback on specific features and functions
- to ask for general feedback on the system
- to troubleshoot any issues arising with the system
- test requests for change and feedback from users as part of future development work
- clarify understandings of pathways and referral processes

Adhoc engagement and responses will be documented and recorded between steering group meetings via email and final sign off if required by the steering group.

Papers and agenda items

Standard agenda items will include:

- welcome & introductions
- system performance feedback
- matters arising over the past period
- system development updates
- specific requests for change and future development proposals
- data and research requests submitted and progress
- patient and patient representatives feedback
- data managers group feedback
- next meeting arrangements

Communications

Meetings will be held virtually wherever possible using facilities such as MS Teams or Zooms. For ad hoc communications and requests for advice, the user group will be engaged as a whole, via email. Depending on the level and nature of response, this may be followed up with targeted phone calls or individual email conversations. Feedback and any decisions made in response to these communications will be shared with the whole group.

Following user group meetings, minutes which make actions and decisions clear will be circulated to the group by the programme team.

Review

The steering committee will be formed from September 2020. A review of these TOR will take place at the first meeting in September 2020. The Terms of reference will be reviewed annually from the date of the final agreed version.