

**Criteria for Assessing Requests for data from the National Haemoglobinopathy Registry**

1. **Criteria for assessing data requests for NHR data for non-research purposes:**

Data requests must clearly set out the purpose for which the data requested will be used and these must have a recognised legal basis.

NHSE may specify certain terms and conditions in any data sharing agreement

1. **Criteria for assessing data requests for NHR data for research purposes:**
* Data requests must clearly set out in detail what the expected benefit of the research will be:

for people living with of affected by Sickle Cell Disease, Thalassaemia or other rare anaemias,

for the treatment and care of people living with or affected by of Sickle Cell Disease, Thalassaemia or other rare anaemias,

for the existing body of knowledge regarding Sickle Cell Disease, Thalassaemia or other rare anaemias,

* Personal identifiers will not be given to researchers unless they have appropriate ethics and NHS Health Research Authority approval (Confidentiality Approval Panel (CAG) S251 for Research
* Patient Identifiable data will not be shared with most organisations including commercial entities. In most instances they will receive reports created by NHSE using aggregated data
* Patient Individual-level data will not to be given to non-UK based entities. Any pseudonymised data will only be shared with countries outside UK which are on the UK GDPR ‘safe list.’
* Additional terms and conditions for data usage or analysis will be specified in the Data Sharing Agreement
* There will also be a number of technical criteria which must be met and these will be assessed as part of the data access request process. These will include: Data storage and data security arrangements (these must be fully described in the data access request and show that the requesting organisation has completed the NHSD DSP Toolkit, meets GDPR, data security and data protection legislation).