

The NHR Dataset is broken down into three main data collection types:

1. Patient Data

Consent Obtained	Yes / No
NHS number	Unique patient identifier
Title	Patient title e.g. Mr, Mrs etc
Forename	Patient Forename
Surname	Patient Surname
Gender	Male / Female
Date of Birth	Date of Birth of the Patient
Ethnicity	NHS standard list of ethnicities
Post code	Patient post code
GP practice code	Code to identify location of GP Practice
Year of diagnosis	When patient was diagnosed
Diagnosis	Patient diagnosis
Therapy	Treatment method patient receiving e.g Iron Chelation
Therapy type	Specific details of treatment method e.g Deferiprone
Transfusion frequency	If applicable how many transfusions given e.g 0-20, >20-50 etc.
Year of first transfusion	Year first transfusion given to patient
Bone marrow transplant	Yes / No
Receives regular penicillin usage	Yes / No
TCD monitoring	Yes / No
Regular Transfusion	Yes / No
Other Comments	Other Comments

2. Adverse Events

NHR Patient Consent Obtained	Yes / No
NHS Number	Unique Patient Identifier
Gender	Male / Female
Diagnosis	Patient diagnosis
Event Type	The type of event e.g. death
Date of event	The date which the event took place
Age of patient	The patients age in months (up to 1 st year), or years
Other Information	Any other relevant information

3. Annual Review

Management Plan	
Date Set	Date when management plan was set
Date Completed	Date when management plan was completed
Todo Action	The action required to be undertaken within the management plan
About the patient	
Date of Annual Review	The date when the annual review was due for completion
Patient failed to attend	Whether the patient attended or not
Height (cm)	The patients height in cm
Weight (kg)	The patients weight in kg
Spleen Size (cm)	The patients spleen size in cm
Centre change in this review period	Yes / No
Patient Status	The patients status e.g. active, no longer seen etc
Date of no longer seen	The date when the patient was no longer seen
Date of death	The date of the patients death
Transferred to	Which centre the patient was transferred to
Date transferred to	The date of when the patient transfer took place
Centre type	Specialist Haemoglobinopathy Team (SHTC) or Secondary Care Centre - Local (LHT)
Number of hospital admissions in this review period	The number of times the patient has been admitted during the review period
Have they had a transfusion in this review period	Yes / No
Has there been a pregnancy in this review period	Yes / No
Outcome of pregnancy	e.g. C section, live birth etc
Complications	
Hepatitis C Status	Whether the patient has Hepatitis C
Date of Hepatitis C status	The date of when the status was diagnosed
HIV Status	Whether the patient has HIV
Date of HIV status	The date of when the status was diagnosed
Therapy initiated or continued in this review period	
Therapy	Treatment method patient receiving e.g Iron Chelation
Therapy type	Specific details of treatment method e.g Deferiprone
Transfusion frequency	If applicable how many transfusions given e.g 0-20, >20-50 etc.
Therapy start / end date	When therapy was started and completed
Vaccinations in this review period	
Vaccination	Details of vaccination received during period e.g. meningitis

Date of Vaccination	The date of when the vaccination took place
Expiry of vaccination	When the vaccination expires
Comments	Any comments related to the vaccination
Serious adverse events in this review period	
Serious Adverse Event	Additional adverse events during the review period not already reported
Reason for ITU admission	Why the patient was admitted
Pulmonary Hypertension Proof	How pulmonary hypertension was proved
Date of serious adverse event	The date of when the serious event took place
Comments	Any further comments relating to the event
Other Complications	
Bone Problems	Whether the patient has had any bone problems e.g. fracture
Endocrinopathy Detail	Detail of endocrinopathy reported e.g. diabetes
Endocrinopathy start date	When the patient was diagnosed with the endocrinopathy
Endocrinopathy continued	Whether the endocrinopathy has still present
Comments	Any further comments relating to the endocrinopathy
Investigations in this Review Period	
Investigation details	What investigation have occurred during the review period e.g. audiometry, blood pressure etc.
Results	
Myocardial	Myocardial test score
Hepatic	Hepatic test score
Liver Iron Concentration	Liver Iron Concentration test score
Medications in this review period	
Medication	Medication that the patient has use during the review period
Medication start date	When the medication was started
Medication end date	When the medication was finished
Medication continued	Whether any further medication is required
Comments	Any comments relating to medications taken
Operations in this review period	
Operation	The type of operation the patient undertook during the review period
Date of operation	When the operation took place
Comments	Any comments relating to the operation
Any other comments	Addition space where further comments can be added to the patients review.