



What details are held in the data records of the patient Optional and Mandatory fields

Demographic and patient identifier data

NHS number	optional
Full name	mandatory
Post code	Deprivation score, geographical analysis
GP registration code	mandatory
Date of birth	mandatory
Date of death	mandatory
gender	mandatory
Ethnicity NHS standard list	mandatory
Education/employment	Optional, deprivation index
Country of birth	Optional Social deprivation index, support genotype
Year of diagnosis	mandatory
diagnosis	mandatory
height	optional
weight	optional

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

Primary fields for identification of centres and other providers shared with NHSE as part of SSQD returns on centre level data:

local centre: mandatory
 Specialist centre: mandatory
 Haemoglobinopathy coordinating centre: mandatory
 Other centres providing care: optional
 Consent obtained for research: optional

Core data for SSQD returns annual review tab and commissioning for care: Mandatory fields

Scheduled Admissions for daycase	Number in last financial year	Commissioning resources
emergency department attendance	Number in last financial year	Commissioning resources
number of unscheduled inpatient admissions in hospital	Number in last financial year	Commissioning resources
bed days in hospital in fiscal year (inpatient stay)	Number in last financial year	Commissioning resources
has the patient required access to psychology services to support their care	Yes/no/don't know	Commissioning resources
Did the patient receive psychology support to help support their care	Yes/no/don't know	Commissioning resources
has patient required other mental health support services	Yes/no/don't know	Commissioning resources
has the patient accessed haemoglobinopathy community services	Yes/no/ don't know/not available	Commissioning resources
was the patient discussed at National MDT panel	Yes /no	Commissioning resources
was the patient eligible for hydroxycarbamide	Yes /no	SSQD

was the patient offered hydroxycarbamide	Yes/no	SSQD
was hydroxycarbamide declined	Yes/no	SSQD
Was the patient eligible for cardiac MRI assessment this year	Yes/no	SSQD
Pregnancy in this year	Yes/no	Health outcomes
Fathered a child this year	Yes/no	Health outcomes
Was this related to a previously documented comorbidity		Not mandatory

Genetic/phenotypic data

Red cell genotype	NHSBT data share	Not anonymised
Red blood cell phenotype	NHSBT datashare	Not anonymised
Antibodies identified	NHSBT datashare and possibly local centre	Not anonymised
Haemoglobinopathy or other genetic diagnosis	Kept on NHR records, only for use by NHP panel (patient level, non anonymised MDT) and commissioners (anonymised as n=x) for assessing patient eligibility for novel therapies	Report Number of patients with specific genetic mutation which is eligible for therapy (not currently on NHR as this field needs development 2.12.20)

Surgical procedures current or previous: all are optional : select procedure and enter date and additional notes if required such as side of replacement

splenectomy	Date of procedure
Hip replacement	
Shoulder replacement	
Knee replacement	
cholecystectomy	
tonsillectomy	
adenoidectomy	
adenotonsillectomy	
Cochlear implant	
Retinal surgery	
Pacemaker insertion	
Pulmonary endarterectomy	
Coronary artery bypass	
Coronary artery stent	
Renal transplant	
Allogenic bone marrow transplant	Date and type of transplant
Gene therapy transplant	Date and type
Liver transplant	
Liver resection	
Resection of mass	Site of resection
Penile stent	
Penile implant	
nephrostomy	
Penile aspiration	
Permanent indwelling cvc> 4 weeks	
AV fistula	

Comorbidities/ complications from disease or other conditions: all optional select and add date of diagnosis, for some severity or grade needed

cardiorespiratory		additional information
	pneumonia	
	acute chest syndrome	
	cardiac failure	
	cardiac arrhythmia	
	pulmonary hypertension	
	myocardial infarction	
	pulmonary embolism	
	deep vein thrombosis	

	asthma	
	obstructive lung disease	
	restrictive lung disease	
	valvular heart disease	
	superior venocaval obstruction secondary to previous central lines	
	other thrombotic complication related to central catheter	
	angina	
	fat embolism syndrome	
genitourinary		
	acute renal failure	
	chronic renal failure	
	renal stones	
	hematuria	
	glomerulonephritis	
	nephrotic syndrome	
	papillary necrosis	
	priapism	
	hydronephrosis	
	renal mass/tumour	
	renal replacement therapy	
orthopaedic	fracture	date and Note: site
	acute osteomyelitis	date and Note: site
	chronic osteomyelitis	date and Note: site
	septic arthritis	date and Note: site
	avascular necrosis	date and Note :: site
	Osteopenia	date and Note :: site
	Osteoporosis	date and Note :: site
	degenerative disc disease	date and Note :: site
	leg ulcers	date and Note :: site
	extramedullary haemopoiesis	date and Note :: site
neurological	ischemic stroke	
	haemorrhagic stroke	
	silent cerebral infarct	
	central venous thrombosis	
	epilepsy	
	seizure without diagnosis of epilepsy	
	spinal cord compression	
	visual loss	
	retinopathy	Severity and grade
	chronic pain	
	moya moya	
haematological	acute haemolytic event not related to blood transfusion	
	pure red cell aplasia	
	neutropenia	
	agranulocytosis	
	disseminated intravascular coagulation	
hepatobiliary	liver failure	
	intrahepatic cholestasis	
	cholestasis	
	biliary colic	
	ascending cholangitis	
	acute pancreatitis	
	pancreatic exocrine insufficiency	
	liver cirrhosis	
	liver fibrosis	
	fatty liver	
	hepatocellular carcinoma	
	acute infective hepatitis	
	hepatic mass	
endocrine		

	insulin dependent diabetes	
	non-insulin dependent diabetes	
	diet controlled diabetes	
	hypothyroidism	
	hypoparathyroidism	
	adrenal insufficiency	
	hypogonadotropic hypogonadism	
	other endocrine complication	
Obstetric/ gynaecological	intrauterine death	
	recurrent miscarriage	
bacterial infection	E Coli, Pneumococcus, salmonella, Klebsiella, coagulase negative staphylococcus, other (free text)	
viral infection	influenza	
	Covid 19	will link into short form and long form
	parvovirus	
	hepatitis A	
	hepatitis B	
	hepatitis C	
	Hepatitis E	
	Other viral illness	
other	cancer (specify site)	
	Other complication not listed above	snomed
	Acute painful crisis (sickle cell)	
Death	If yes selected then will ask for cause of death and if linked to underlying complication	

Immunisations in post splenectomy patients and sickle cell disease: optional select immunisation add date

Pneumococcal vaccine 13 valent	date
Pneumococcal vaccine 23 valent	date
Meningitis B	date
Meningitis ACYW	date
Meningitis C/Hib	date
Annual influenza	date
Hepatitis B	date

Medications and Therapies: all optional, select from drop down and add date of starting and date of end of therapy

disease modifying therapy	chelation regimen	endocrine	other therapy
hydroxycarbamide	deferasirox	levothyroxine	penicillin
prednisolone	deferiprone	insulin	penicillin alternative
dexamethasone	desferrioxamine	oral hypoglycaemic agent	ace inhibitor
interferon	desferrioxamine and deferiprone	calcitriol (rocaltriol)	angiotensin receptor blocker
Other (text box)	deferasirox and deferiprone	hydrocortisone	bisphosphonate
	deferasirox and desferrioxamine	growth hormone	opioid therapy
		testosterone replacement therapy	warfarin
		Ostrogen and progesterone replacement therapy (not added in the context of contraception)	NOAC/DOAC
		fertility therapy	anti platelet therapy
			vitamin D
			pancreatic enzyme supplement
future drugs to be added in as they are licenced			folic acid
			home oxygen

			renal replacement therapy
			sildenafil
			etilefrine

Transfusion reactions: (optional) and drop down boxes

Reaction	If yes then choose:
Acute Haemolytic Transfusion Reaction (HTR Acute)	Associated with a new antibody (conventional DHTR)
	associated with previous antibody
	not thought to be associated with antibody: hyperhaemolysis
Delayed Haemolytic Transfusion Reaction (HTR Delayed)	Associated with a new antibody (conventional DHTR)
	associated with previous antibody
	not thought to be associated with antibody: hyperhaemolysis

Transfusion therapy: (optional) select transfusion tab, then type of therapy

adhoc or regular transfusion	Select type
modality of transfusion	top up
	manual exchange transfusion
	automated exchange transfusion
interval between transfusions	weeks:: 1,2,3,4,5,6,7,8,9,10,,11,12 (max 12)
number of units pRBC per transfusion	units: 1,2,3,4,5,6,7,8,9,10,11,12 (max 12)
average mls per transfusion (for children below 16 only)	

Monitoring fields: all optional even if part of SSQD

Cardiac T2*	Date of scan and report in milliseconds
Liver T2*	date of scan and report in milliseconds or mg/g/dw
ferriscan Liver iron	Date of scan and report in mg/g/dw
ejection fraction %	Date and Result _ % drop down selection for method:: MRI or ECHO
TCD report as : done yes or no:	Date and result reported as follows drop down selection: normal :: conditional:: abnormal :: unrecordable (new fields being developed for velocities and QC underway)
Bone densitometry	Date and result reported as: drop down selection:: osteoporosis:: osteopenia:: normal

Other assessments	
ophthalmology assessment	Date and result: Normal or abnormal
Audiology assessment	Date and result: Normal or abnormal
Echocardiography:	Date and result: TR Jet velocity value
Ultrasound scan	Date and result can be entered as free text
Endoscopy:	Date and result
ERG	Date and result normal or abnormal
creatinine	Date and result
HbSAb	Date and result
HCV Antibody	Date and result
HCV RNA	Date and result
Alpha fetoprotein	Date and result
glucose tolerance test	Date and result. Normal or abnormal
ferritin	Date and result
AST	Date and result
total bilirubin	Date and result
FSH	Date and result
LH	Date and result
Testosterone	Date and result
Oestrogen	Date and result
TSH	Date and result
FT4	Date and result
PTH	Date and result
vitamin D3 total	Date and result
Hb pre transfusion	Date and result
steady state Hb	Date and result
HbF % for untransfused patients on Hydroxycarbamide	Date and result
HbA % for regularly transfused patients with HbS pre transfusion	Date and result

fructosamine	Date and result
urine Calcium	Date and result
urine pr:creatinine ratio	Date and result
urine albumin:creatinine ratio	Date and result

screened or enrolled in clinical trial: yes/ no
if yes : clinical trial /study number