



National Haemoglobinopathy Registry

ANNUAL REPORT 2025/26

Contents

Chapter 1: Introduction	2
Chapter 2: Sickle Cell Reports	3
Chapter 3: Thalassaemia Reports.....	9
Chapter 4: Rare Inherited Anaemia Reports	15
Chapter 5: Serious Events and Comorbidities	21

Figures

Figure 1 - Sickle Cell patients by diagnosis type.....	4
Figure 2 - Sickle Cell patients by ethnicity	4
Figure 3 - Sickle Cell patients by age group	5
Figure 4 - Sickle Cell patients by treatment type.....	6
Figure 5 - Sickle Cell patients by iron chelation type	6
Figure 6 - Sickle Cell patients - Regular transfusions by modality.....	8
Figure 7 - Thalassaemia patients by diagnosis type.....	10
Figure 8 - Thalassaemia patients by ethnicity	10
Figure 9 - Thalassaemia patients by age group.....	11
Figure 10 - Thalassaemia patients by treatment type (excluding other therapy).....	12
Figure 11 - Thalassaemia patients - Regular transfusions by modality	14
Figure 12 - Rare inherited anaemia patients by diagnosis type.....	16
Figure 13 - Rare inherited anaemia patients by ethnicity.....	16
Figure 14 - Rare inherited anaemia patients by age group.....	17
Figure 15 - Rare inherited anaemia patients by treatment type (excluding other therapy)	18
Figure 16 - Rare inherited anaemia patients - Treatments	19
Figure 17 - Rare inherited anaemia patients - Regular transfusions by modality.....	20

Tables

Table 1 - Inactive Patients	2
Table 2 - Sickle Cell patients by SHT	3
Table 3 - Sickle Cell patients by HCC	5
Table 4 - Sickle Cell patient treatments	7
Table 5 - Sickle Cell patients with TCD monitoring by HCC	8
Table 6 - Thalassaemia patients by SHT	9
Table 7 - Thalassaemia patients by HCC	11
Table 8 - Thalassaemia patients - Treatments.....	13
Table 9 - Rare inherited anaemia patients by HCC	17
Table 10 - Sickle Cell patients - Serious adverse events.....	21
Table 11 - Sickle Cell patients - Comorbidities	22
Table 12 - Thalassaemia patients – Serious adverse events	23
Table 13 - Thalassaemia patients – Comorbidities.....	23
Table 14 - Rare inherited anaemia patients - Serious adverse events.....	23
Table 15 - Rare inherited anaemia patients - Comorbidities.....	23

Chapter 1: Introduction

The 2025/26 Annual Data Report provides stakeholders of the NHR with an update on patient numbers for Sickle Cell, Thalassaemia and other rare inherited anaemia patients in England.

The removal of inactive patients from reporting is necessary to maintain an accurate portrayal of patient populations.

Table 1 details the number of patients that have become inactive during the year. We encourage users of the NHR to update the status of their patients accordingly.

Status	No.
Deceased	110
Emigrated	72

Table 1 - Inactive Patients

The data shown in the report is based on information entered by treatment centres. Ongoing data quality and assurance programmes are in place to improve and ensure the highest quality of data.

Chapter 2: Sickle Cell Reports

Sickle Cell patients by SHT

SHT Name	Active Patients
King's College Hospital NHS Foundation Trust	1455
Guy's and St Thomas' NHS Foundation Trust	1410
Barts Health NHS Trust	1359
Manchester University NHS Foundation Trust	1138
Midland Metropolitan University Hospital - Adults (Sandwell and West Birmingham Hospitals NHS Trust)	1055
Lewisham and Greenwich NHS Trust	807
North Middlesex University Hospital NHS Trust	727
Imperial College Healthcare NHS Trust	721
St Georges Healthcare NHS Foundation Trust	713
Oxford University Hospitals NHS Foundation Trust	651
Barking Havering and Redbridge University Hospital Trust	617
Birmingham Children's Hospital - Paediatrics (Birmingham Women and Children's NHS Trust)	614
London Northwest University Healthcare NHS Trust	571
University Hospitals of Leicester NHS Trust	514
Whittington Health NHS Trust	473
Nottingham University Hospitals NHS Trust	432
University College Hospitals NHS Foundation Trust	430
University Hospitals Bristol & Weston NHS Foundation Trust	393
Croydon Health Services NHS Trust	392
The Newcastle Upon Tyne Hospitals NHS Foundation Trust	340
Homerton Healthcare NHS Foundation Trust	339
Leeds Teaching Hospitals NHS Trust	338
Royal Liverpool University Hospital (Liverpool University Hospitals NHS Foundation Trust)	281
St James's (Leeds Teaching Hospitals NHS Trust)	279
Addenbrooke's Hospital Cambridge (Cambridge University Hospitals NHS Foundation Trust)	278
University Hospital Southampton NHS Foundation Trust	236
Sheffield Teaching Hospitals NHS Foundation Trust	181
University Hospital of Wales (Cardiff and Vale University Health Board)	159
Sheffield Children's NHS Foundation Trust	124
Birmingham Women's and Children's Hospital NHS FT and Sandwell and West Birmingham Hospitals NHS Trust	35
No SHT specified	162

Table 2 - Sickle Cell patients by SHT

Sickle Cell patients by diagnosis type

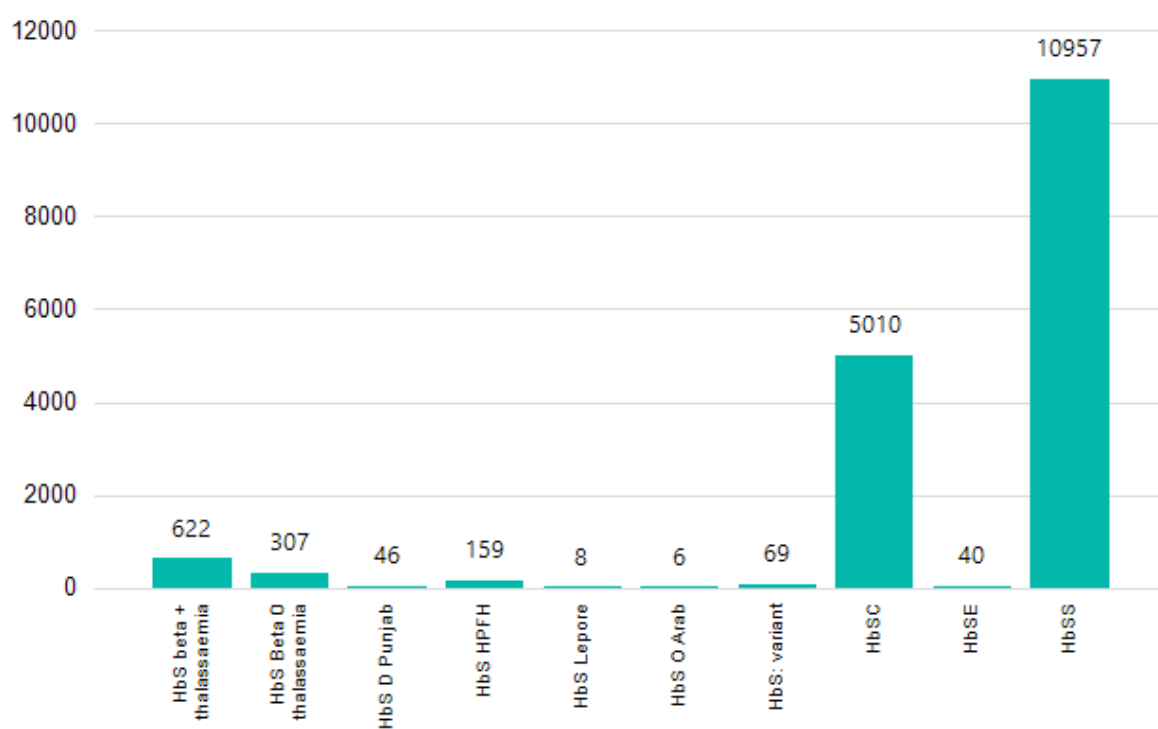


Figure 1 - Sickle Cell patients by diagnosis type

Sickle Cell patients by ethnicity

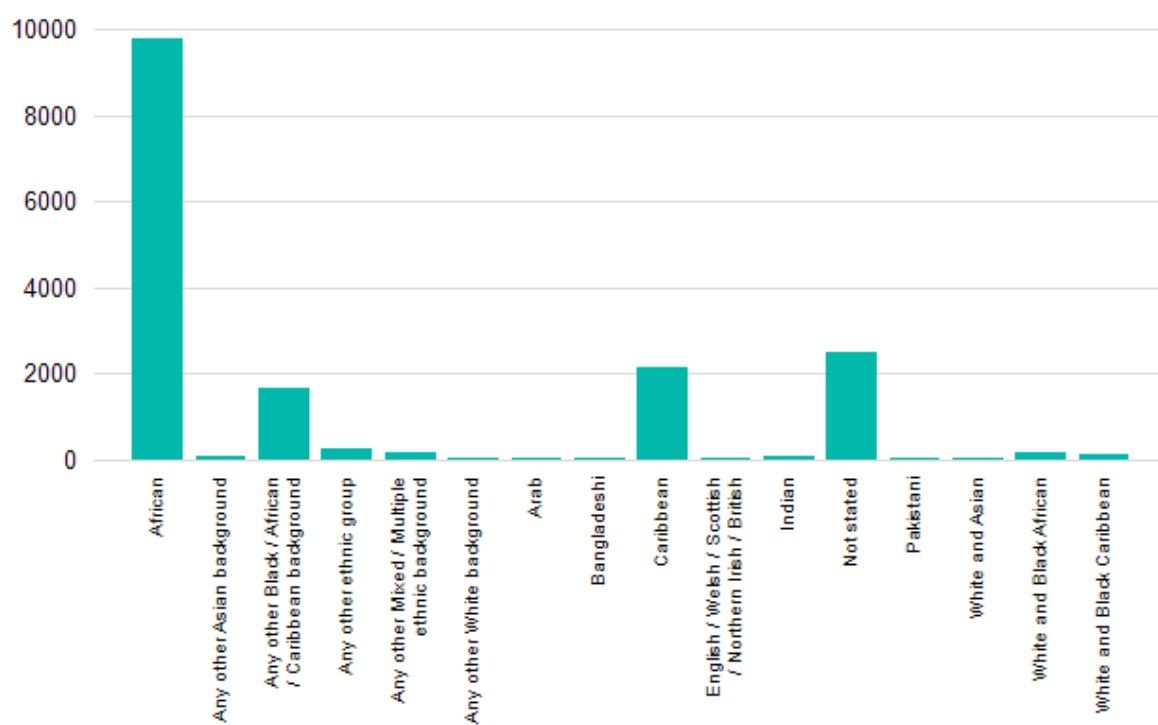


Figure 2 - Sickle Cell patients by ethnicity

Sickle Cell patients by HCC

HCC Name	Active Patients
South East London and South East	4071
East London and Essex	2317
West London	2123
North Central London and East Anglia	1924
West Midlands	1698
North West	1401
North East and Yorkshire	1261
East Midlands	949
Wessex and Thames Valley	883
South West	418
North	11
Midlands	<5
No HCC specified	164

Table 3 - Sickle Cell patients by HCC

Sickle Cell patients by age group

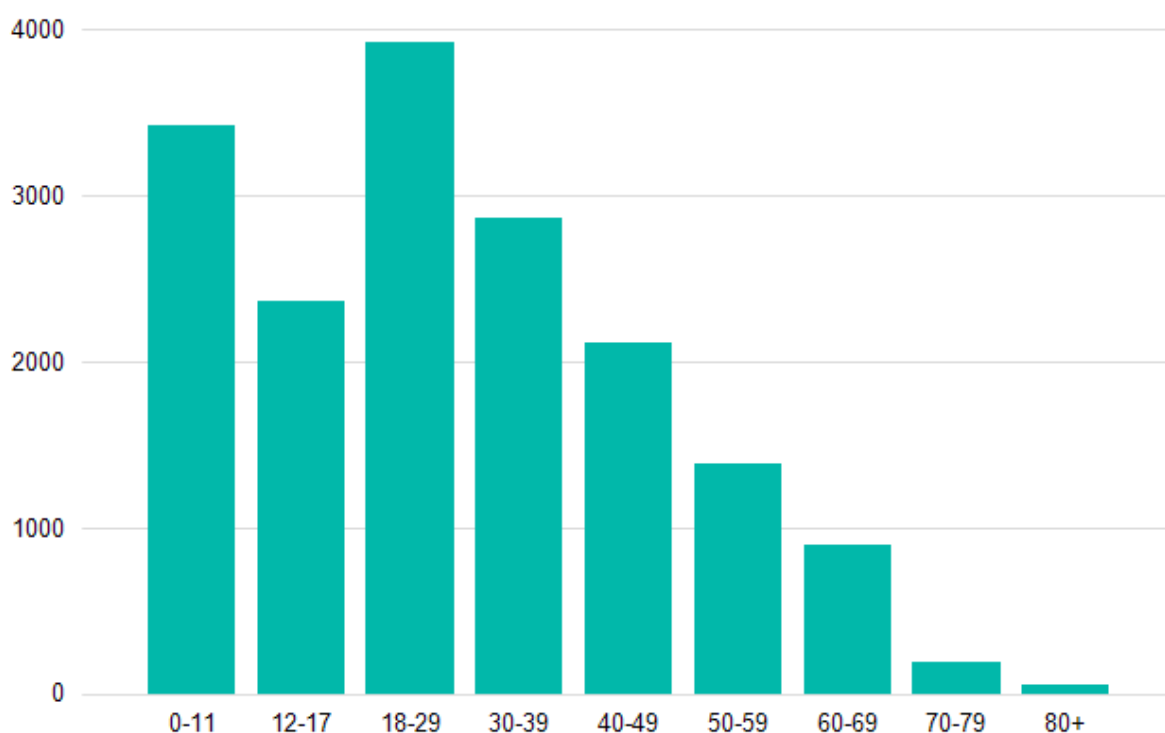


Figure 3 - Sickle Cell patients by age group

Sickle Cell patients by treatment type (excluding other therapy)

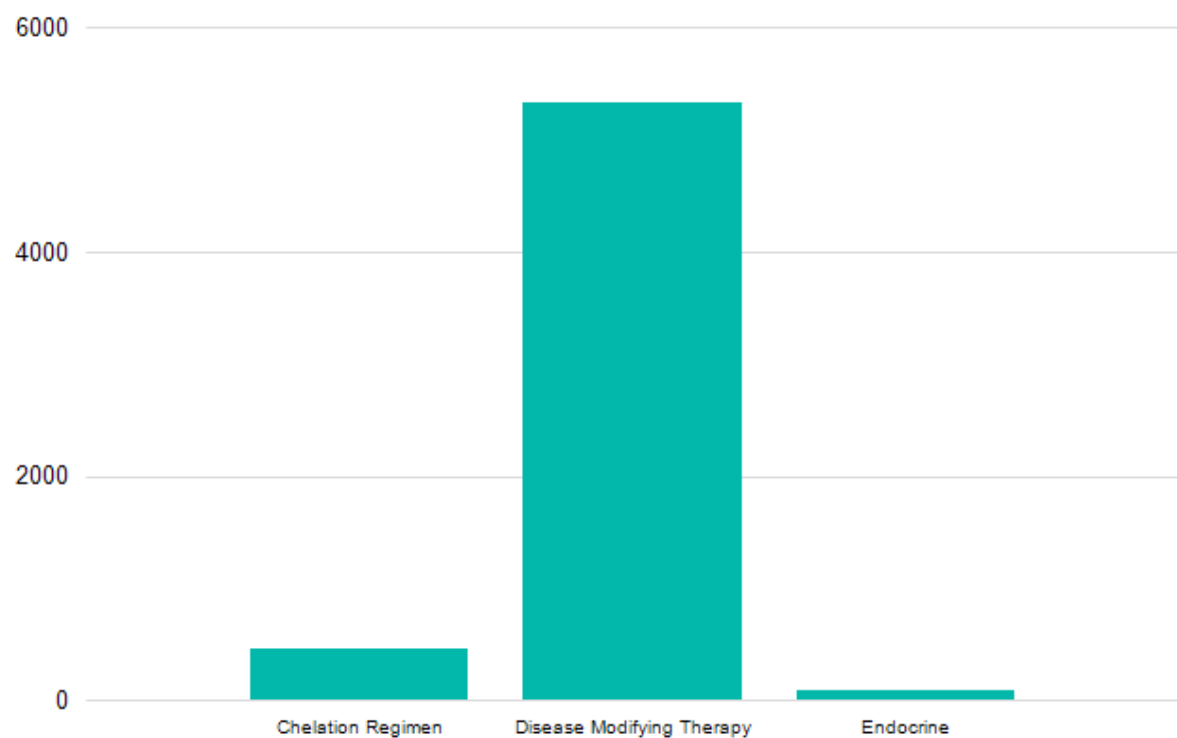


Figure 4 - Sickle Cell patients by treatment type

Sickle Cell patients by iron chelation type

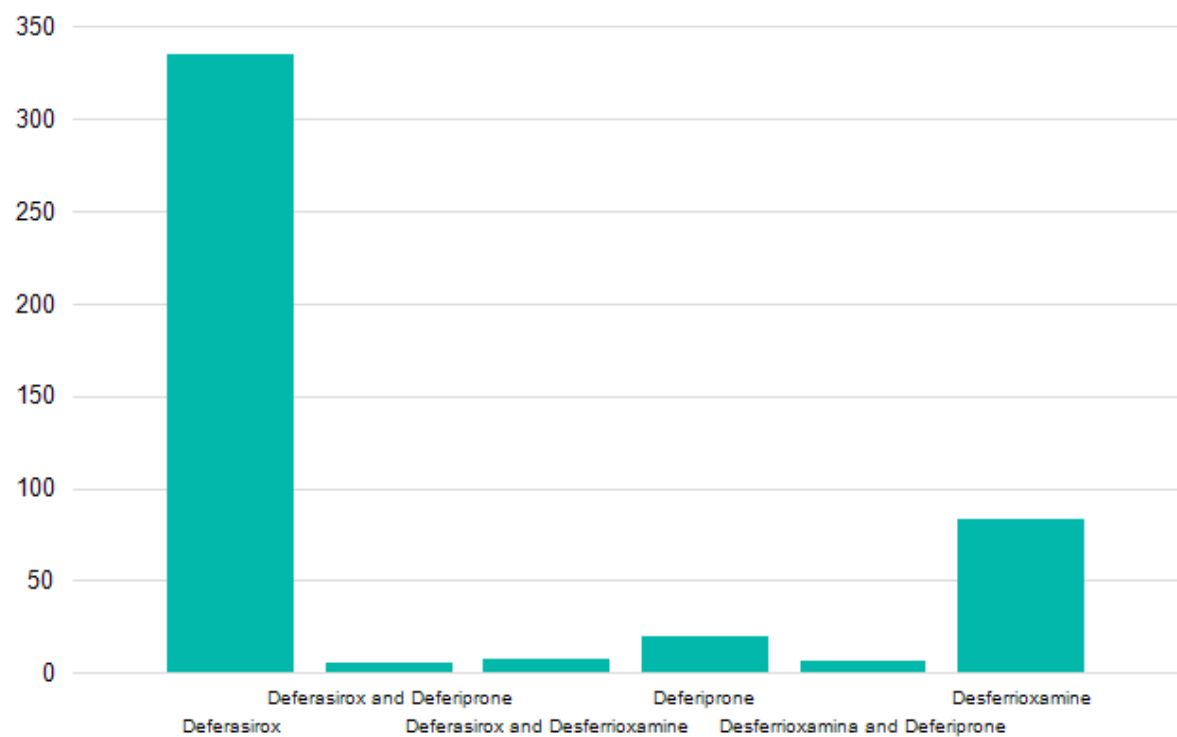


Figure 5 - Sickle Cell patients by iron chelation type

Sickle Cell patient treatments

Treatment Group Id	Treatment	No.
Chelation Regimen	Deferasirox	335
	Desferrioxamine	83
	Deferiprone	20
	Deferasirox and Desferrioxamine	7
	Desferrioxamine and Deferiprone	6
	Deferasirox and Deferiprone	5
Disease Modifying Therapy	Hydroxycarbamide	5275
	Prednisolone	34
	Other	14
	Dexamethasone	<5
Endocrine	Levothyroxine	36
	Insulin	24
	Hydrocortisone	13
	Oral hypoglycaemic agent	8
	Oestrogen and progesterone replacement therapy	6
	Calcitriol (rocaltriol)	<5
	Growth hormone	<5
	Testosterone replacement therapy	<5
Other Therapy	Folic acid	8297
	Penicillin	8176
	Other	5915
	Vitamin D	2528
	Opioid therapy	302
	Penicillin alternative	168
	ACE inhibitor	97
	NOAC/DOAC	73
	Crizanlizumab	56
	Voxelotor	43
	Warfarin	41
	Etielofrine	11
	Angiotensin receptor blocker	9
	Sildenafil	9
	Home oxygen	8
	Antiplatelet therapy	7
	Bisphosphonate	6
	Pancreatic enzyme supplement	<5
	Renal replacement therapy	<5

Table 4 - Sickle Cell patient treatments

Data shown is as directly entered onto the NHR by treatment centres.

Sickle Cell patients regular transfusions

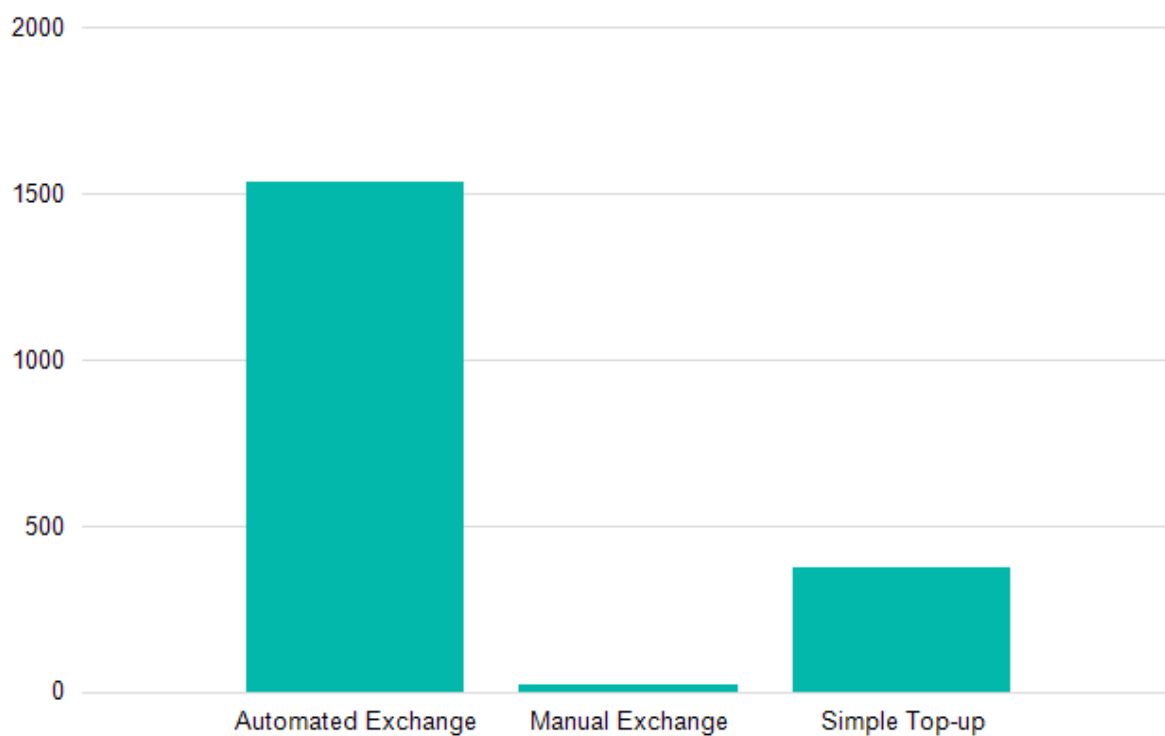


Figure 6 - Sickle Cell patients - Regular transfusions by modality

Sickle Cell patients with TCD (Transcranial Doppler) monitoring by HCC

HCC Name	Patients
South East London and South East	644
West Midlands	355
East London and Essex	347
North East and Yorkshire	340
West London	333
North West	318
North Central London and East Anglia	256
East Midlands	194
Wessex and Thames Valley	177
South West	108
North	<5
No HCC specified	18

Table 5 - Sickle Cell patients with TCD monitoring by HCC

Chapter 3: Thalassaemia Reports

Thalassaemia patients by SHT

SHT Name	Active Patients
Manchester University NHS Foundation Trust	222
University College Hospitals NHS Foundation Trust	214
Whittington Health NHS Trust	214
Midland Metropolitan University Hospital - Adults (Sandwell and West Birmingham Hospitals NHS Trust)	191
Barts Health NHS Trust	175
Birmingham Children's Hospital - Paediatrics (Birmingham Women and Children's NHS Trust)	148
Imperial College Healthcare NHS Trust	132
Leeds Teaching Hospitals NHS Trust	107
Oxford University Hospitals NHS Foundation Trust	101
London Northwest University Healthcare NHS Trust	93
University Hospitals of Leicester NHS Trust	83
University Hospitals Bristol & Weston NHS Foundation Trust	75
St Georges Healthcare NHS Foundation Trust	73
Nottingham University Hospitals NHS Trust	71
King's College Hospital NHS Foundation Trust	59
North Middlesex University Hospital NHS Trust	59
St James's (Leeds Teaching Hospitals NHS Trust)	59
Guy's and St Thomas' NHS Foundation Trust	57
Royal Liverpool University Hospital (Liverpool University Hospitals NHS Foundation Trust)	50
The Newcastle Upon Tyne Hospitals NHS Foundation Trust	47
Barking Havering and Redbridge University Hospital Trust	42
Sheffield Teaching Hospitals NHS Foundation Trust	35
University Hospital Southampton NHS Foundation Trust	31
Lewisham and Greenwich NHS Trust	27
Addenbrooke's Hospital Cambridge (Cambridge University Hospitals NHS Foundation Trust)	19
Sheffield Children's NHS Foundation Trust	16
Homerton Healthcare NHS Foundation Trust	15
University Hospital of Wales (Cardiff and Vale University Health Board)	15
Croydon Health Services NHS Trust	5
Birmingham Women's and Children's Hospital NHS FT and Sandwell and West Birmingham Hospitals NHS Trust	<5
No SHT specified	<5

Table 6 - Thalassaemia patients by SHT

Thalassaemia patients by diagnosis type

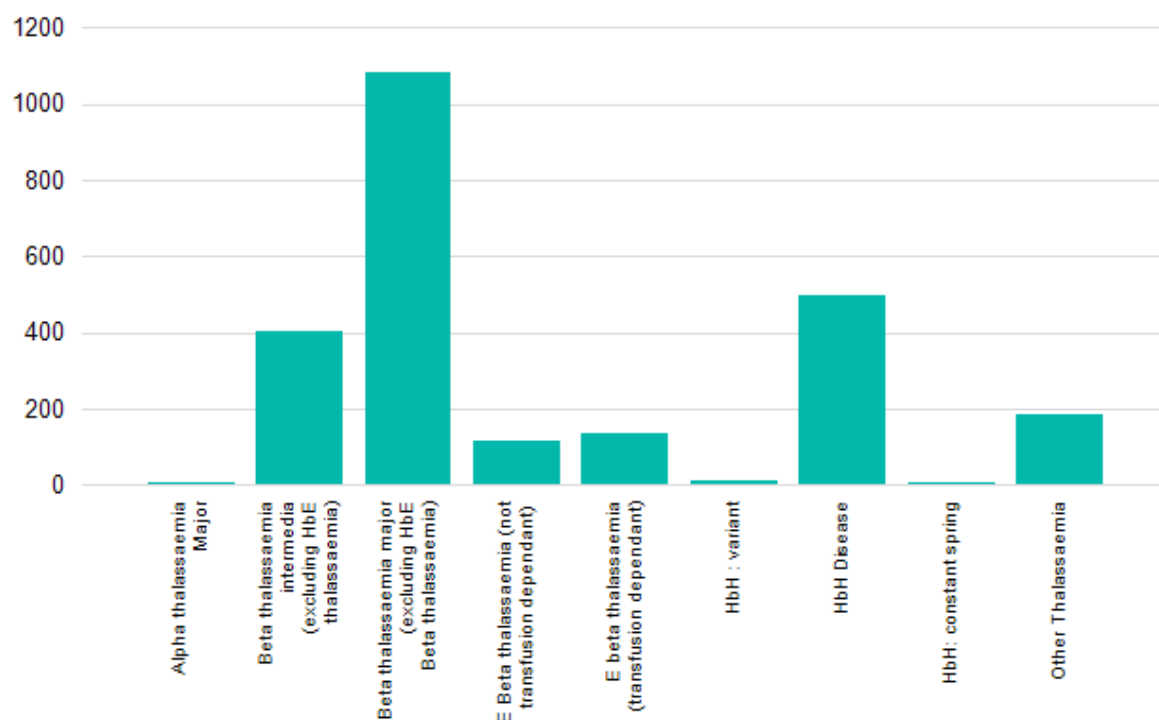


Figure 7 - Thalassaemia patients by diagnosis type

Thalassaemia patients by ethnicity

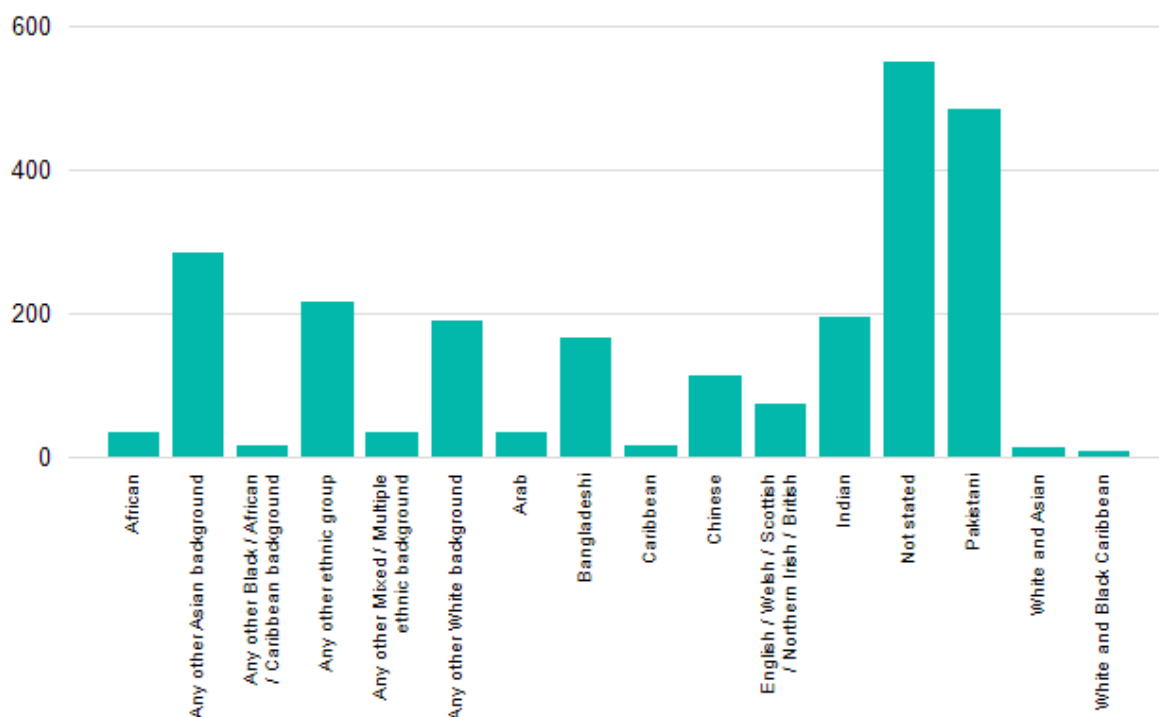


Figure 8 - Thalassaemia patients by ethnicity

Thalassaemia patients by HCC

HCC Name	Active Patients
London, South Central and South West	1027
North	523
Midlands	494
London and South East	374
North West	13
East Midlands	<5
South East London and South East	<5
Wessex and Thames Valley	<5
No HCC specified	<5

Table 7 - Thalassaemia patients by HCC

Thalassaemia patients by age group

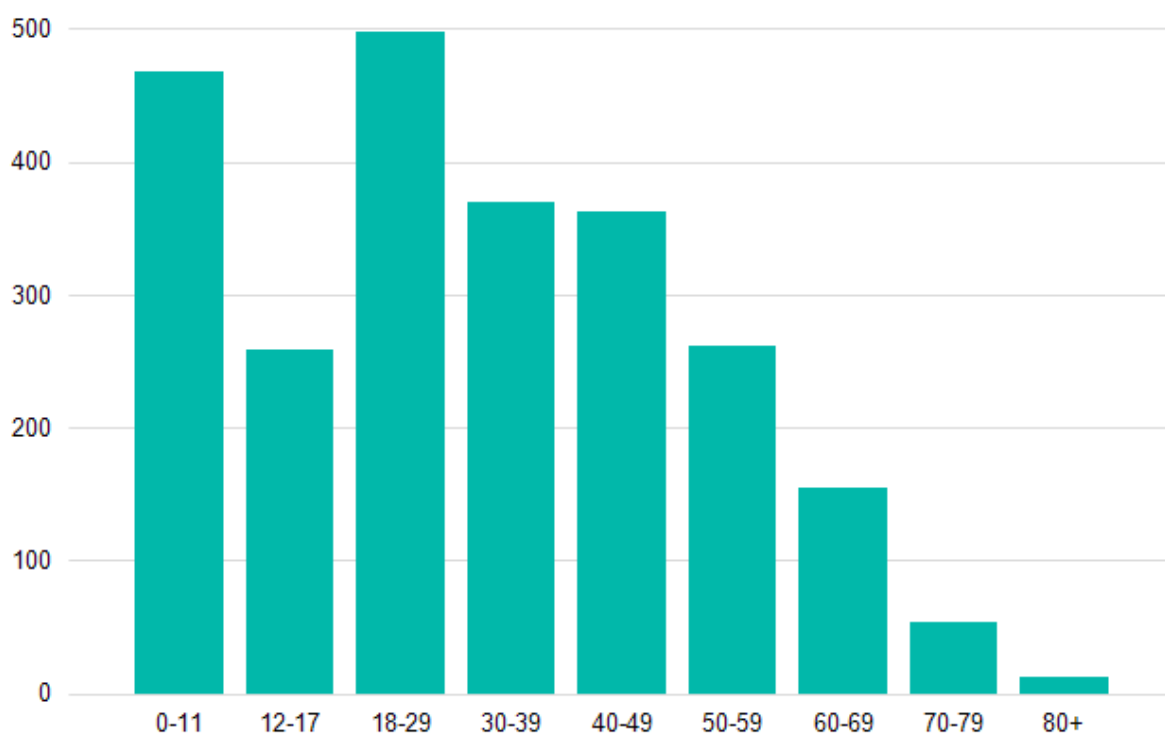


Figure 9 - Thalassaemia patients by age group

Thalassaemia patients by treatment type (excluding other therapy)

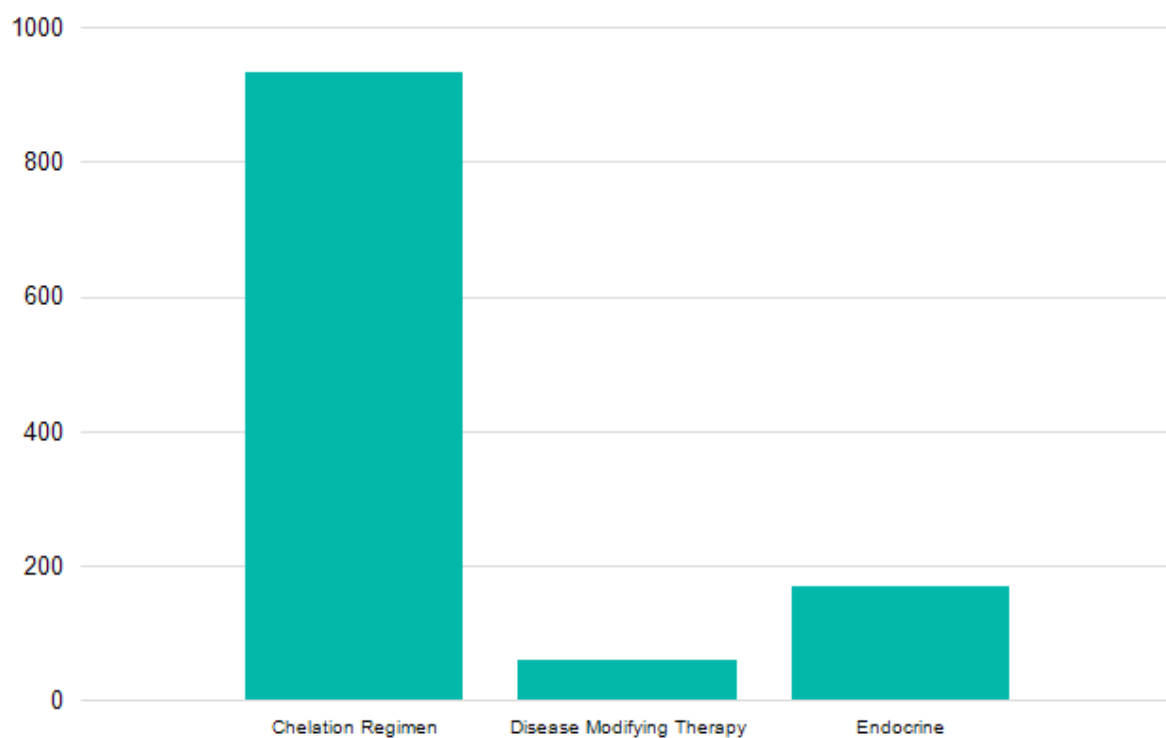


Figure 10 - Thalassaemia patients by treatment type (excluding other therapy)

Thalassaemia patients - Treatments

Treatment group	Treatment	No.
Chelation Regimen	Deferasirox	587
	Desferrioxamine	135
	Deferiprone	90
	Deferasirox and Deferiprone	47
	Desferrioxamine and Deferiprone	38
	Deferasirox and Desferrioxamine	37
Disease Modifying Therapy	Hydroxycarbamide	54
	Other	5
Endocrine	Levothyroxine	55
	Testosterone replacement therapy	44
	Insulin	37
	Oestrogen and progesterone replacement therapy	15
	Growth hormone	11
	Calcitriol (rocaltriol)	<5
	Hydrocortisone	<5
	Oral hypoglycaemic agent	<5
Other Therapy	Other	803
	Folic acid	519
	Vitamin D	465
	Penicillin	153
	Warfarin	15
	Bisphosphonate	11
	NOAC/DOAC	8
	Sildenafil	6
	Penicillin alternative	5
	ACE inhibitor	<5
	Opioid therapy	<5
	Pancreatic enzyme supplement	<5

Table 8 - Thalassaemia patients - Treatments

Data shown is as directly entered onto the NHR by treatment centres.

Thalassaemia patients regular transfusions

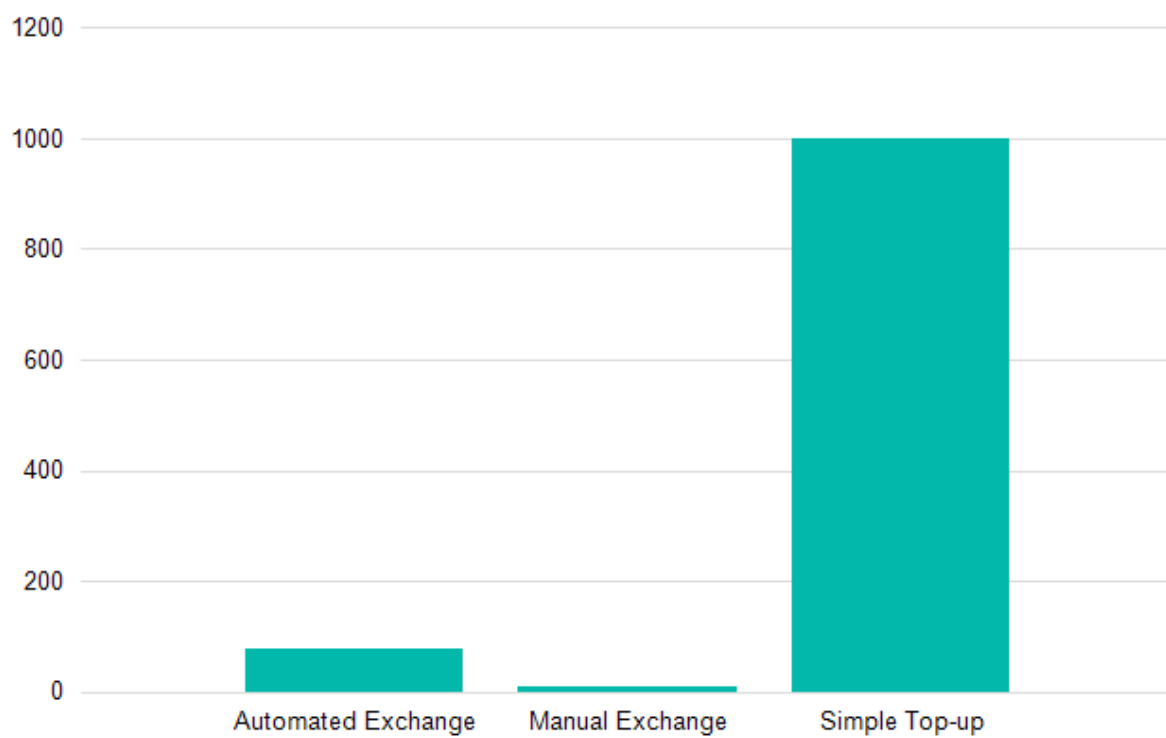


Figure 11 - Thalassaemia patients - Regular transfusions by modality

Chapter 4: Rare Inherited Anaemia Reports

Rare inherited anaemia patients by SHT

SHT Name	Active Patients
Manchester University NHS Foundation Trust	88
Oxford University Hospitals NHS Foundation Trust	61
Midland Metropolitan University Hospital - Adults (Sandwell and West Birmingham Hospitals NHS Trust)	52
The Newcastle Upon Tyne Hospitals NHS Foundation Trust	49
Barking Havering and Redbridge University Hospital Trust	45
University College Hospitals NHS Foundation Trust	45
Barts Health NHS Trust	41
Nottingham University Hospitals NHS Trust	40
Imperial College Healthcare NHS Trust	38
Royal Liverpool University Hospital (Liverpool University Hospitals NHS Foundation Trust)	38
Birmingham Children's Hospital - Paediatrics (Birmingham Women and Children's NHS Trust)	36
University Hospitals Bristol & Weston NHS Foundation Trust	34
London Northwest University Healthcare NHS Trust	33
St Georges Healthcare NHS Foundation Trust	30
University Hospitals of Leicester NHS Trust	26
Addenbrooke's Hospital Cambridge (Cambridge University Hospitals NHS Foundation Trust)	25
Sheffield Teaching Hospitals NHS Foundation Trust	24
University Hospital Southampton NHS Foundation Trust	22
King's College Hospital NHS Foundation Trust	19
University Hospital of Wales (Cardiff and Vale University Health Board)	18
Guy's and St Thomas' NHS Foundation Trust	17
Whittington Health NHS Trust	16
Leeds Teaching Hospitals NHS Trust	13
Lewisham and Greenwich NHS Trust	13
St James's (Leeds Teaching Hospitals NHS Trust)	12
Sheffield Children's NHS Foundation Trust	9
Croydon Health Services NHS Trust	<5
North Middlesex University Hospital NHS Trust	<5
Birmingham Women's and Children's Hospital NHS FT and Sandwell and West Birmingham Hospitals NHS Trust	<5
No SHT specified	41

Rare inherited anaemia patients by diagnosis type

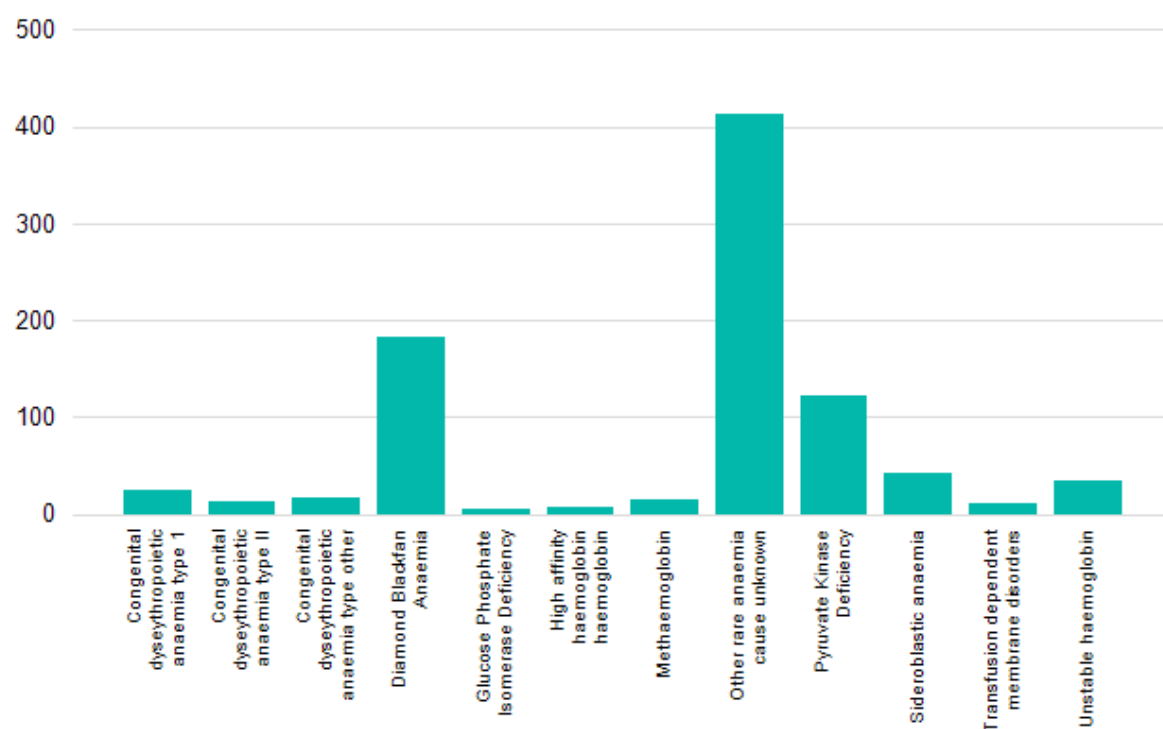


Figure 12 - Rare inherited anaemia patients by diagnosis type

Rare inherited anaemia patients by ethnicity

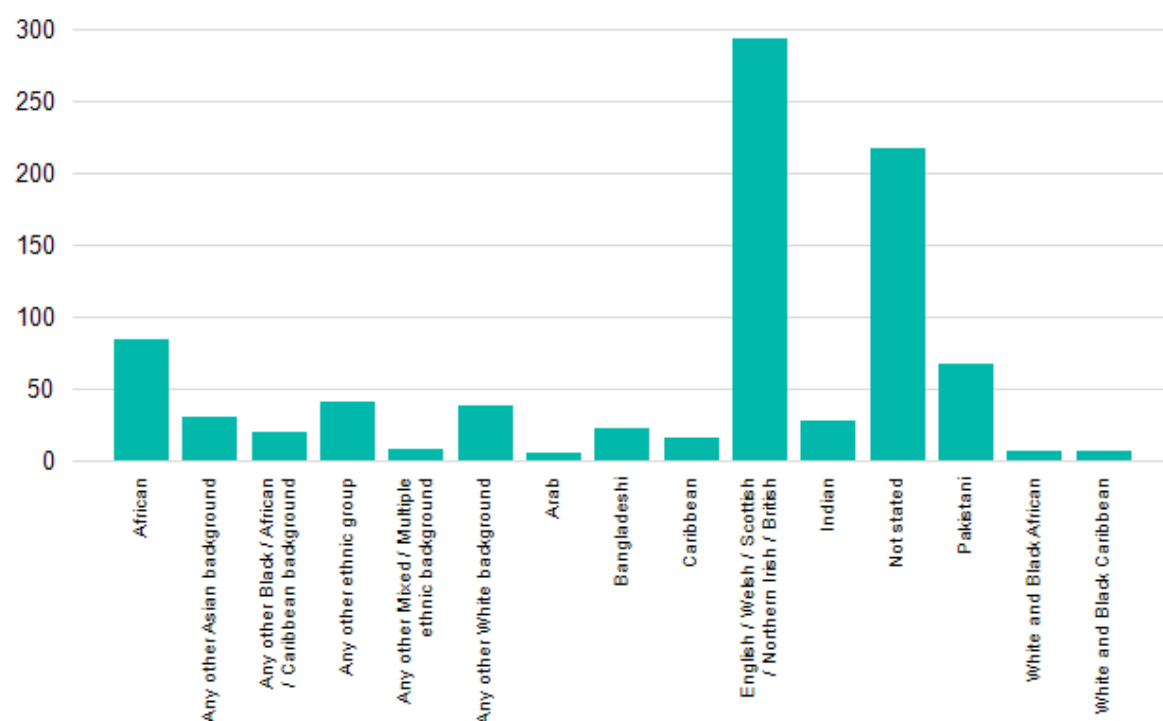


Figure 13 - Rare inherited anaemia patients by ethnicity

Rare inherited anaemia patients by HCC

HCC Name	Active Patients
London, South Central and South West	312
North	219
Midlands	151
London and South East	114
South East London and South East	20
North West	13
East London and Essex	7
Wessex and Thames Valley	5
East Midlands	<5
West London	<5
West Midlands	<5
No HCC specified	43

Table 9 - Rare inherited anaemia patients by HCC

Rare inherited anaemia patients by age group

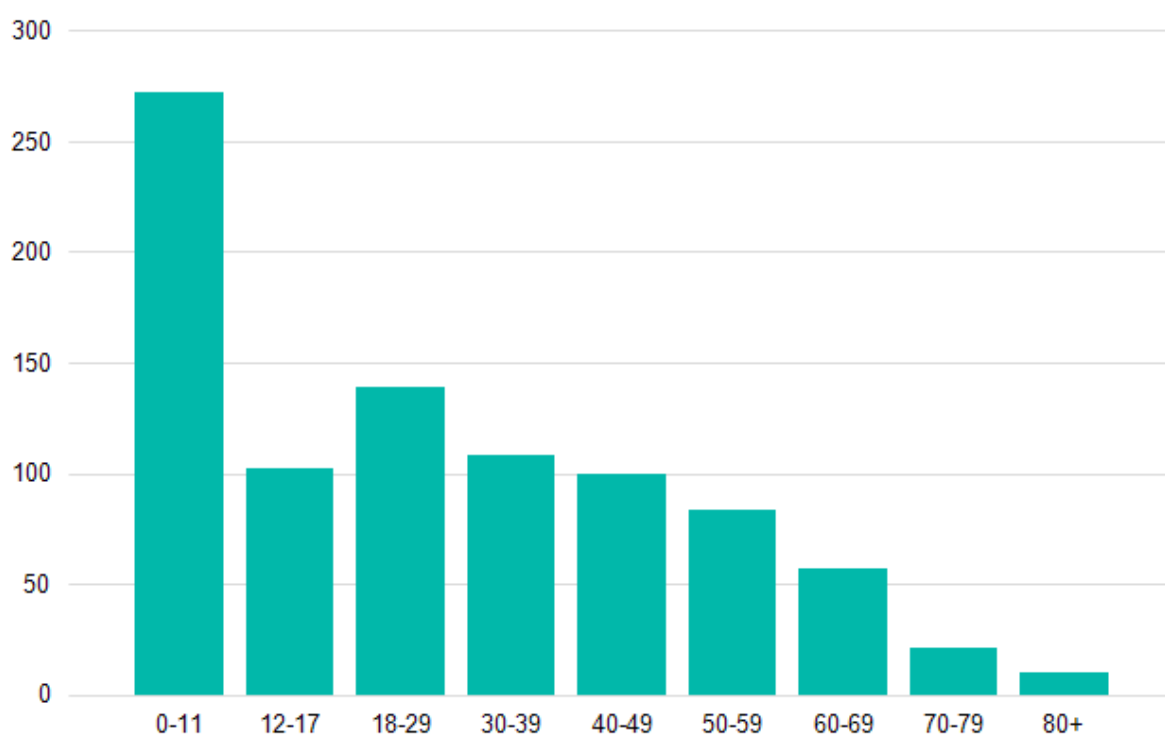


Figure 14 - Rare inherited anaemia patients by age group

Rare inherited anaemia patients by treatment type (excluding other therapy)

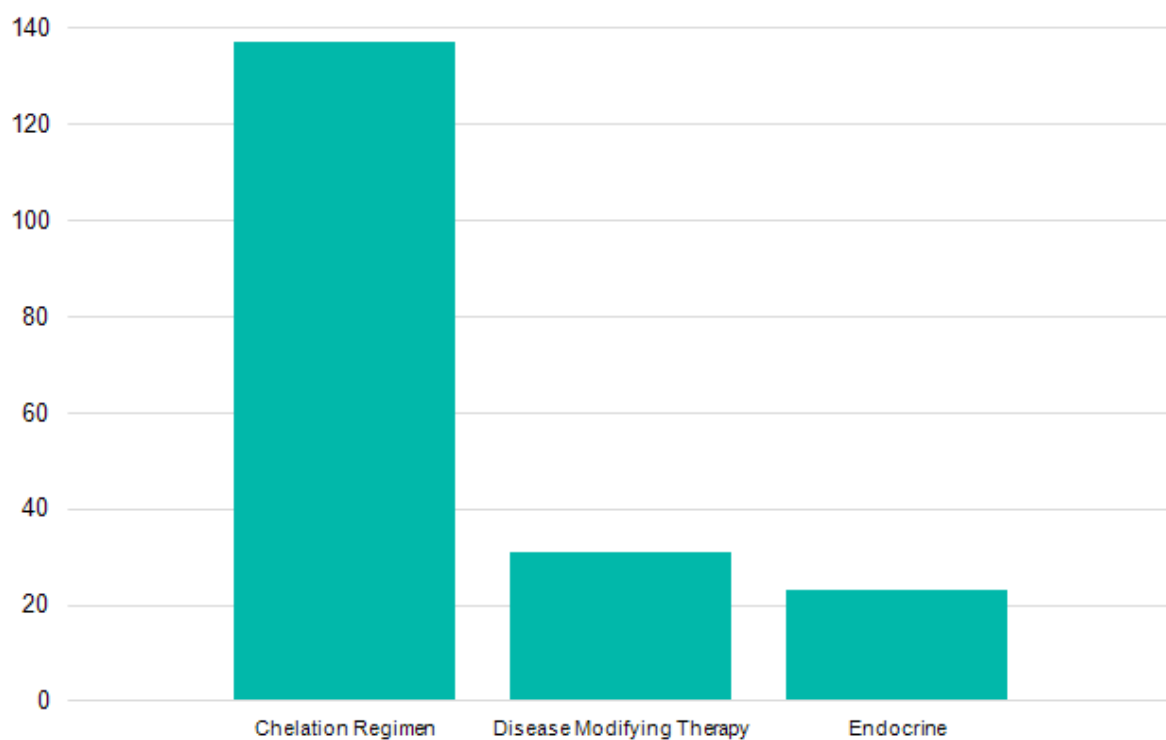


Figure 15 - Rare inherited anaemia patients by treatment type (excluding other therapy)

Rare inherited anaemia patients - Treatments

Treatment group	Treatment	No.
Chelation Regimen	Deferasirox	96
	Desferrioxamine	22
	Deferasirox and Desferrioxamine	8
	Deferiprone	8
	Deferasirox and Deferiprone	<5
	Desferrioxamine and Deferiprone	<5
Disease Modifying Therapy	Prednisolone	17
	Hydroxycarbamide	10
	Interferon	<5
Endocrine	Levothyroxine	11
	Growth hormone	<5
	Hydrocortisone	<5
	Insulin	<5
	Testosterone replacement therapy	<5
Other Therapy	Folic acid	173
	Other	143
	Vitamin D	92
	Penicillin	56
	Bisphosphonate	<5
	Home oxygen	<5
	NOAC/DOAC	<5
	Penicillin alternative	<5
	Warfarin	<5

Figure 16 - Rare inherited anaemia patients - Treatments

Data shown is as directly entered onto the NHR by treatment centres.

Rare inherited anaemia patients regular transfusions

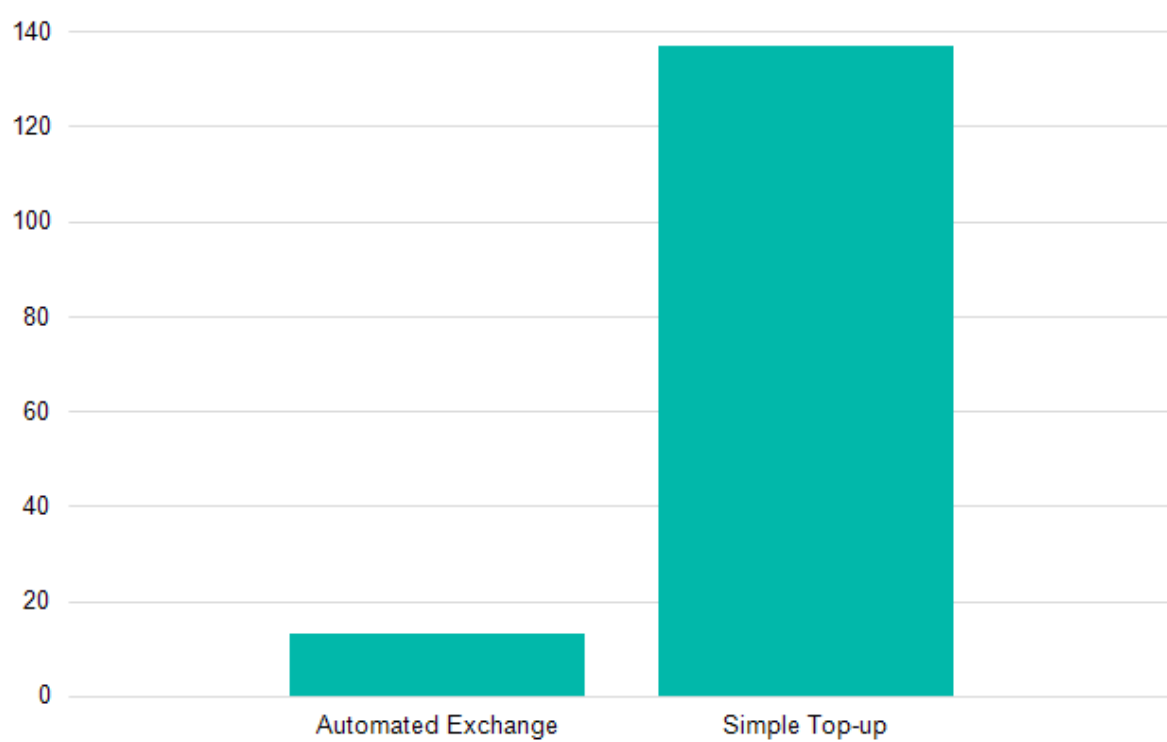


Figure 17 - Rare inherited anaemia patients - Regular transfusions by modality

Chapter 5: Serious Events and Comorbidities

Sickle Cell patients - Serious adverse events 2025/26	No.
Death	79
Ischaemic stroke	17
Delayed HTR - Not thought to be associated with antibody: hyperhaemolysis	14
Haemorrhagic stroke	9
Cardiac failure	5
Delayed HTR - Associated with a new antibody (conventional DHTR)	5
Delayed HTR - Associated with previous antibody	<5
Intrauterine death	<5
Pneumococcal Infection	<5

Table 10 - Sickle Cell patients - Serious adverse events

Sickle Cell patients - Comorbidities 2025/26

Comorbidity type	Comorbidity	No.
Acute Haemolytic Transfusion Reaction (HTR Acute)	Acute HTR - Not thought to be associated with antibody: hyperhaemolysis	<5
Bacterial infection	Bacterial infectious disease (Other)	9
	Salmonella sp.	<5
Cardiorespiratory	Acute chest syndrome	122
	Pulmonary embolism	15
	Pneumonia	12
	Fat embolism syndrome	5
	Asthma	<5
	Deep vein thrombosis	<5
	Myocardial infarction	<5
	Pulmonary hypertension	<5
	Restrictive Lung disease	<5
Endocrine	Insulin dependent diabetes	<5
	Other endocrine complication	<5
Genitourinary	Priapism	16
	Acute renal failure	<5
	Chronic renal failure Stage 3 CKD: eGFR Between 30 and 59	<5
	Chronic renal failure Stage 4 CKD: eGFR Between 15 and 29	<5
	Chronic renal failure Stage 5 CKD: eGFR Less than 15	<5
	Haematuria	<5
Haematological	Simple painful crisis	372
Hepatobiliary	Ascending cholangitis	<5
	Biliary colic	<5
	Liver failure	<5

Neurological disorders	Chronic pain	42
	Epilepsy	<5
	Moyamoya	<5
	Retinopathy Stage I Peripheral arterial occlusion	<5
	Retinopathy Stage II Peripheral arteriovenous anastomoses (hairpin loop)	<5
	Retinopathy Stage IV Vitreous haemorrhage	<5
	Seizure without diagnosis of epilepsy	<5
Orthopaedic	Avascular necrosis	10
	Acute Osteomyelitis	<5
	Chronic Osteomyelitis	<5
	Degenerative disc disease	<5
	Leg ulcers	<5
	Septic arthritis	<5
Other	Other complication not listed above	78
	Splenic sequestration	8
	Cancer	7
Viral infection	Other viral illness	16
	Influenza	15
	Covid 19	6
	Hepatitis B	<5
	Parvovirus	<5

Table 11 - Sickle Cell patients - Comorbidities

Thalassaemia patients - Serious adverse events 2025/26		No.
Death		9
Delayed HTR - Not thought to be associated with antibody: hyperhaemolysis		<5
Pneumococcal Infection		<5

Table 12 - Thalassaemia patients – Serious adverse events

Thalassaemia patients - Comorbidities 2025/26

Comorbidity type	Comorbidity	No.
Bacterial infection	Bacterial infectious disease (Other)	<5
Cardiorespiratory	Deep vein thrombosis	<5
Endocrine	Hypogonadotrophic hypogonadism	<5
Orthopaedic	Extramedullary haemopoiesis	<5
	Osteoporosis	<5
Other	Other complication not listed above	23
	Cancer	<5
Viral infection	Hepatitis B	<5

Table 13 - Thalassaemia patients – Comorbidities

Rare inherited anaemia patients - Serious adverse events 2025/26		No.
Death		6
Cardiac failure		<5

Table 14 - Rare inherited anaemia patients - Serious adverse events

Rare inherited anaemia patients - Comorbidities 2025/26

Comorbidity type	Comorbidity	No.
Obstetric/ gynaecological	Recurrent miscarriage	<5
Other	Other complication not listed above	<5

Table 15 - Rare inherited anaemia patients - Comorbidities