



National Haemoglobinopathy Registry

ANNUAL REPORT 2023/2024

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Chapter 1: Introduction

The 2023/24 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.

Status	No.
Deceased	58
Emigrated	12

Table 1 - Inactive Patients 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	58
Emigrated	12

Table 1 - Inactive Patients.

The data shown in the report is as has been 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

SHT Name	Registrations
Barts Health NHS Trust	1758
Birmingham Women's and Children's Hospital NHS FT and Sandwell and West Birmingham Hospitals NHS Trust	1471
King's College Hospital NHS Foundation Trust	1365
Guy's and St Thomas' NHS Foundation Trust	1328
Lewisham and Greenwich NHS Trust	790
Manchester University NHS Foundation Trust	728
North Middlesex University Hospital NHS Trust	721
St Georges Healthcare NHS Foundation Trust	631
University College London Hospitals NHS Foundation Trust	623
Imperial College Healthcare NHS Trust	576
London Northwest University Healthcare NHS Trust	528
Oxford University Hospitals NHS Foundation Trust	512
Leeds Teaching Hospitals NHS Trust	494
University Hospitals of Leicester NHS Trust	420
Whittington Health NHS Trust	406
Homerton Healthcare NHS Foundation Trust	376
Croydon Health Services NHS Trust	332
Nottingham University Hospitals NHS Trust	312
University Hospitals Bristol & Weston NHS Foundation Trust	273
The Newcastle Upon Tyne Hospitals NHS Foundation Trust	258
Addenbrooke's Hospital Cambridge (Cambridge University Hospitals NHS Foundation Trust)	211
Royal Liverpool University Hospital (Liverpool University Hospitals NHS Foundation Trust)	209
University Hospital Southampton NHS Foundation Trust	150
Sheffield Teaching Hospitals NHS Foundation Trust	139
University Hospital of Wales (Cardiff and Vale University Health Board)	127
Sheffield Children's NHS Foundation Trust	98
Sandwell Hospital - Paediatrics	11
No SHT specified	184

Table 2 - Sickle Cell registrations by SHT.

Sickle Cell patients by diagnosis type

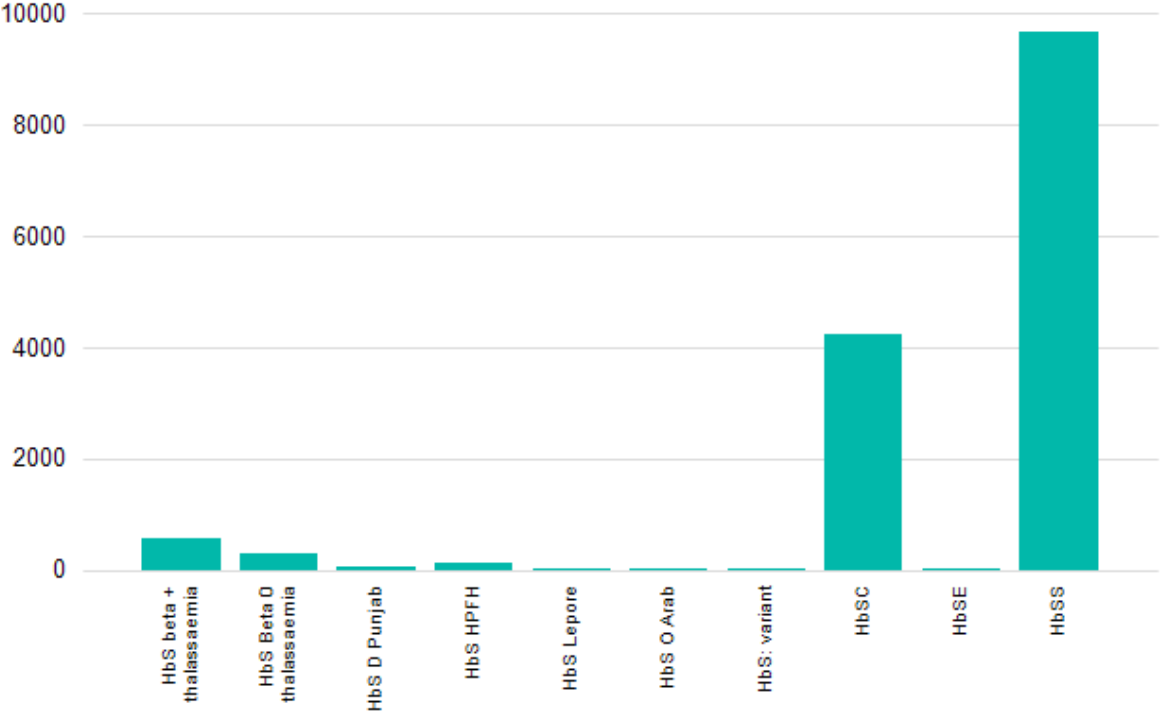


Figure 1 - Sickle Cell patients by diagnosis type.

Sickle Cell patients by ethnicity

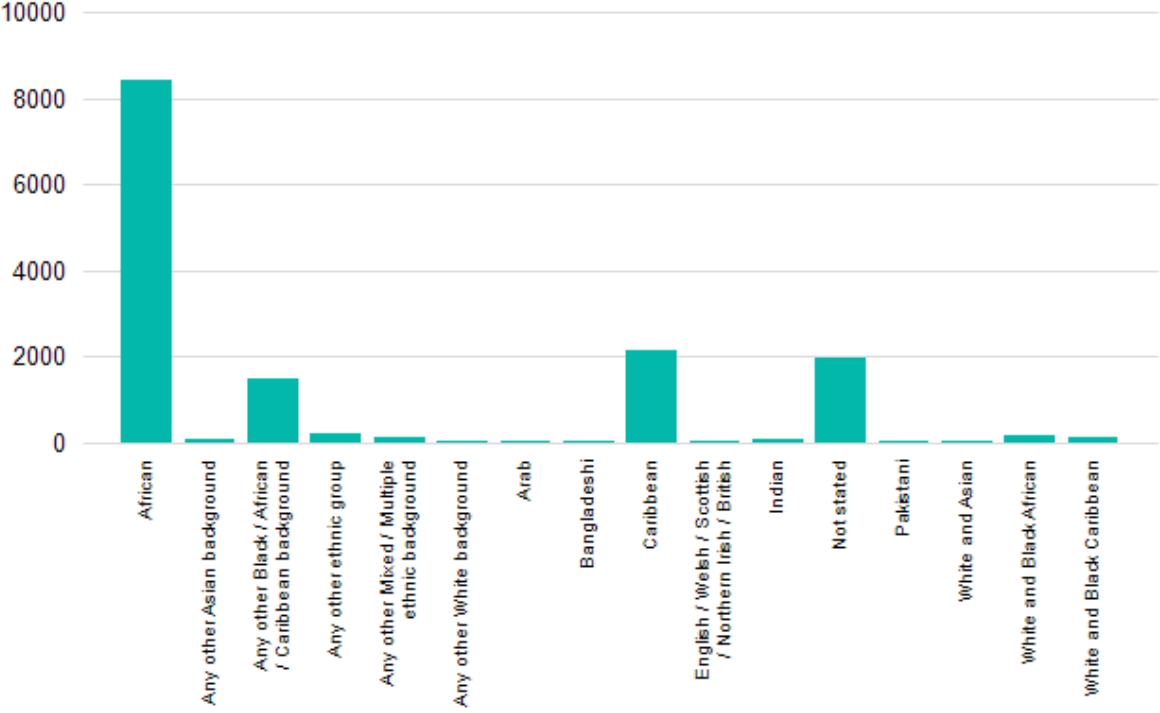


Figure 2 - Sickle Cell patients by ethnicity.

HCC Name	Registrations
South East London and South East	3837
East London and Essex	2158
North Central London and East Anglia	1940
West London	1804
West Midlands	1482
North East and Yorkshire	995
North West	934
East Midlands	725
Wessex and Thames Valley	660
South West	300
London and South East	7
London, South Central and South West	<5
Midlands	<5
North	<5
No HCC specified	182

Table 3 - Sickle Cell registrations by HCC.

Sickle Cell patients by age group

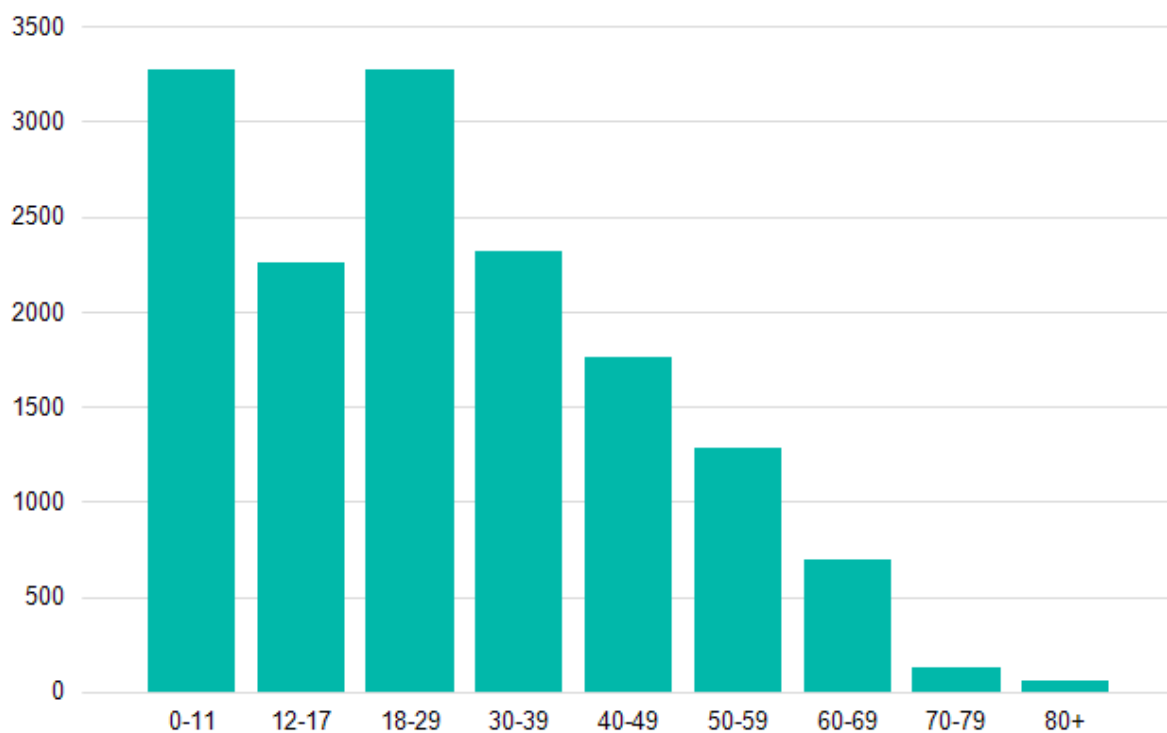


Figure 3 - Sickle Cell patients by age group.

Sickle Cell patients by treatment type (excluding other therapy)

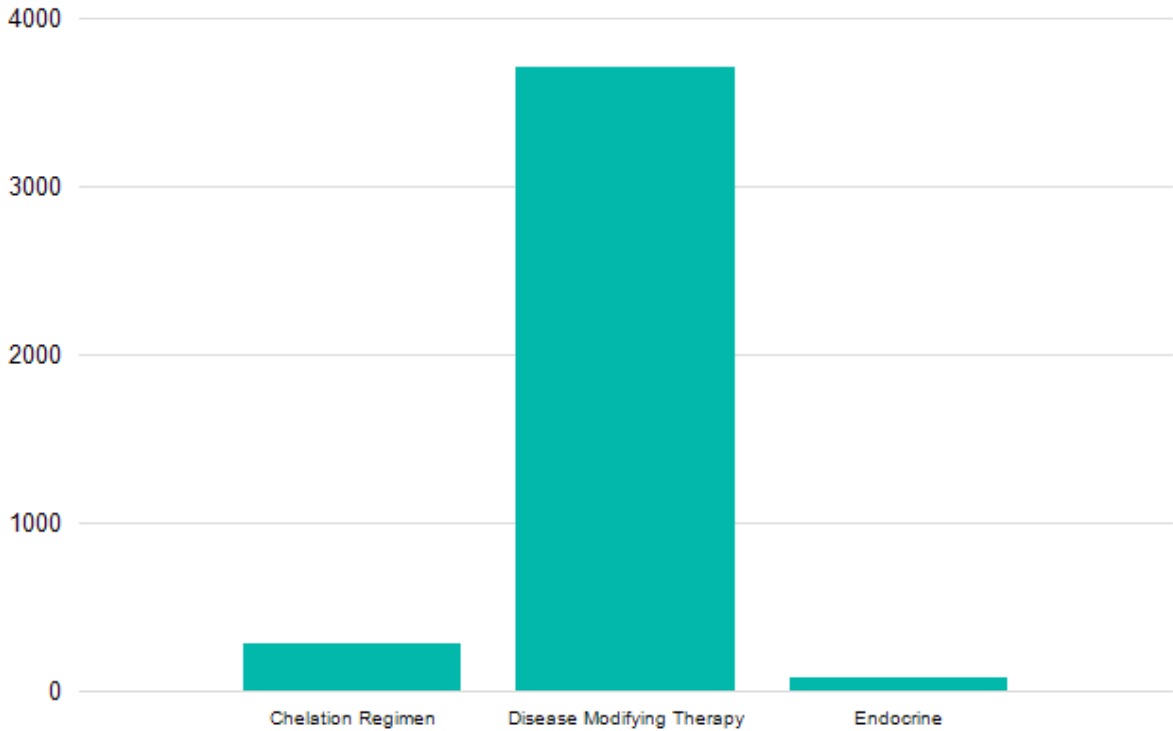


Figure 4 - Sickle Cell patients by treatment type (excluding other therapy).

Sickle Cell patients by iron chelation type

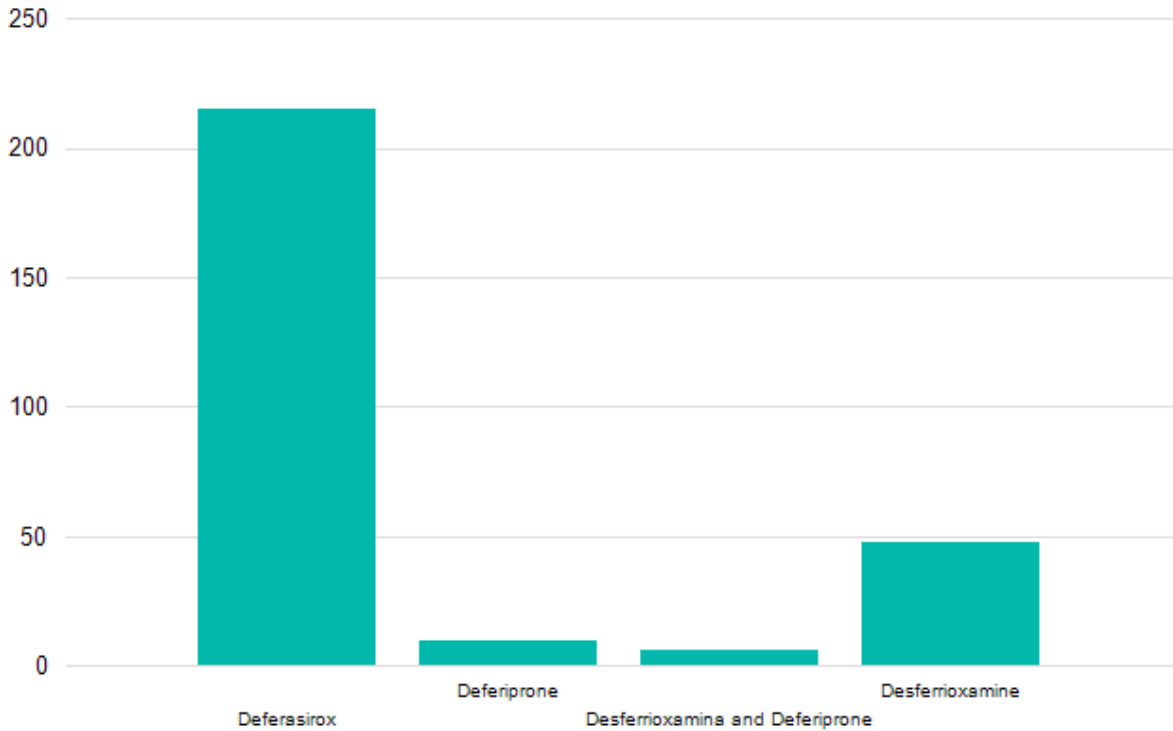


Figure 5 - Sickle Cell patients by iron chelation type.

Treatment type	Treatment	No.
Chelation Regimen	Deferasirox	215
	Desferrioxamine	48
	Deferiprone	10
	Desferrioxamina and Deferiprone	6
	Deferasirox and Deferiprone	<5
	Deferasirox and Desferrioxamine	<5
Disease Modifying Therapy	Hydroxycarbamide	3659
	Prednisolone	31
	Other	15
	Dexamethasone	<5
Endocrine	Levothyroxine	34
	Insulin	22
	Hydrocortisone	12
	Oral hypoglycaemic agent	8
	Oestrogen and progesterone replacement therapy	6
	Calcitriol (rocaltriol)	<5
	Growth hormone	<5
	Testosterone replacement therapy	<5
Other Therapy	Folic acid	5900
	Penicillin	5825
	Other	5218
	Vitamin D	1871
	Opioid therapy	252
	Crizanlizumab	126
	Penicillin alternative	126
	Ace inhibitor	88
	NOAC/DOAC	61
	Voxelotor	60
	Warfarin	42
	Etliefrine	11
	Sildenafil	9
	Angiotensin receptor blocker	8
	Home oxygen	7
	Anti platelet therapy	6
	Bisphosphonate	<5
	Pancreatic enzyme supplement	<5
	Renal replacement therapy	<5

Table 4 - Sickle cell patients by treatment type and number of treatments.

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

Sickle Cell patients regular transfusions

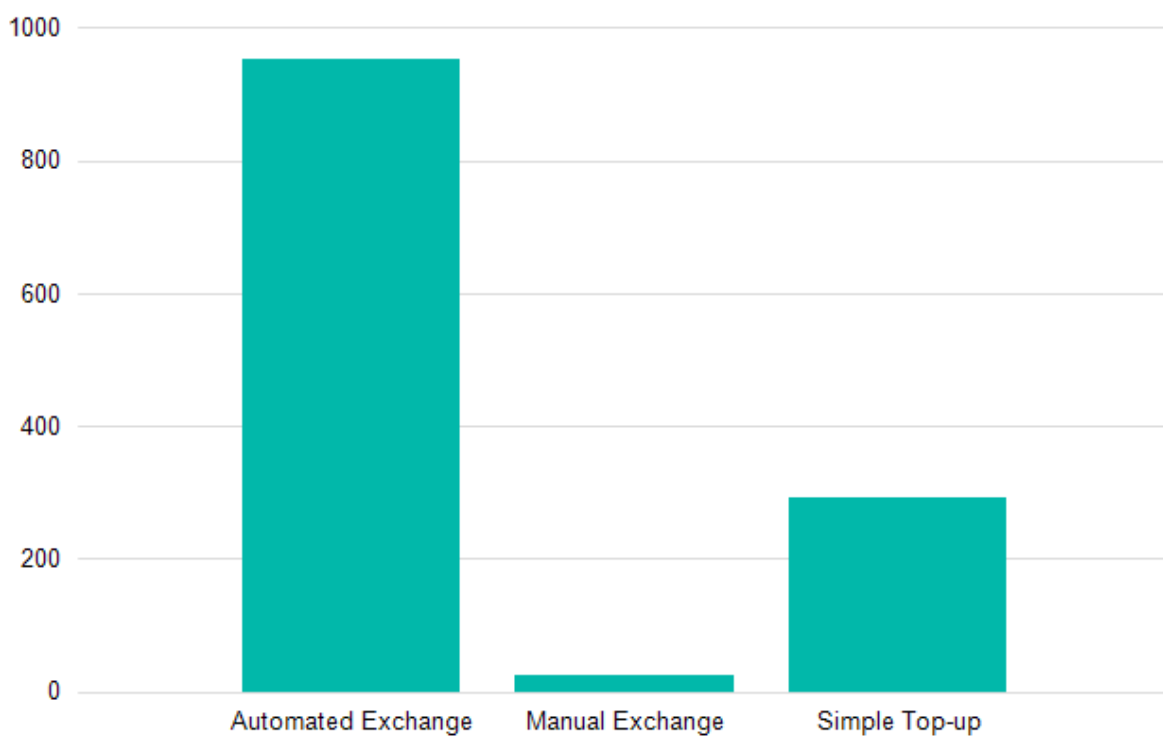


Figure 6 - Sickle Cell patients receiving regular transfusions by modality.

HCC Name	Registrations
South East London and South East	691
East London and Essex	412
North West	335
West Midlands	320
North East and Yorkshire	267
North Central London and East Anglia	226
West London	218
East Midlands	170
Wessex and Thames Valley	150
South West	82
North	<5
No HCC specified	5

Table 5 - Sickle Cell registrations with TCD monitoring by HCC.

Chapter 3: Thalassaemia Reports

SHT Name	Registrations
Birmingham Women's and Children's Hospital NHS FT and Sandwell and West Birmingham Hospitals NHS Trust	321
University College London Hospitals NHS Foundation Trust	230
Whittington Health NHS Trust	223
Barts Health NHS Trust	201
Manchester University NHS Foundation Trust	178
Leeds Teaching Hospitals NHS Trust	144
Imperial College Healthcare NHS Trust	102
Oxford University Hospitals NHS Foundation Trust	76
University Hospitals of Leicester NHS Trust	74
London Northwest University Healthcare NHS Trust	66
North Middlesex University Hospital NHS Trust	64
Nottingham University Hospitals NHS Trust	55
St Georges Healthcare NHS Foundation Trust	55
King's College Hospital NHS Foundation Trust	54
University Hospitals Bristol & Weston NHS Foundation Trust	51
Guy's and St Thomas' NHS Foundation Trust	45
The Newcastle Upon Tyne Hospitals NHS Foundation Trust	40
Royal Liverpool University Hospital (Liverpool University Hospitals NHS Foundation Trust)	30
Sheffield Teaching Hospitals NHS Foundation Trust	28
Lewisham and Greenwich NHS Trust	25
Addenbrooke's Hospital Cambridge (Cambridge University Hospitals NHS Foundation Trust)	18
University Hospital Southampton NHS Foundation Trust	17
Sheffield Children's NHS Foundation Trust	15
University Hospital of Wales (Cardiff and Vale University Health Board)	7
Croydon Health Services NHS Trust	5
Homerton Healthcare NHS Foundation Trust	<5
St James's (Leeds Teaching Hospitals NHS Trust)	<5
No SHT specified	14

Table 6 - Thalassaemia registrations by SHT.

Thalassaemia patients by diagnosis type

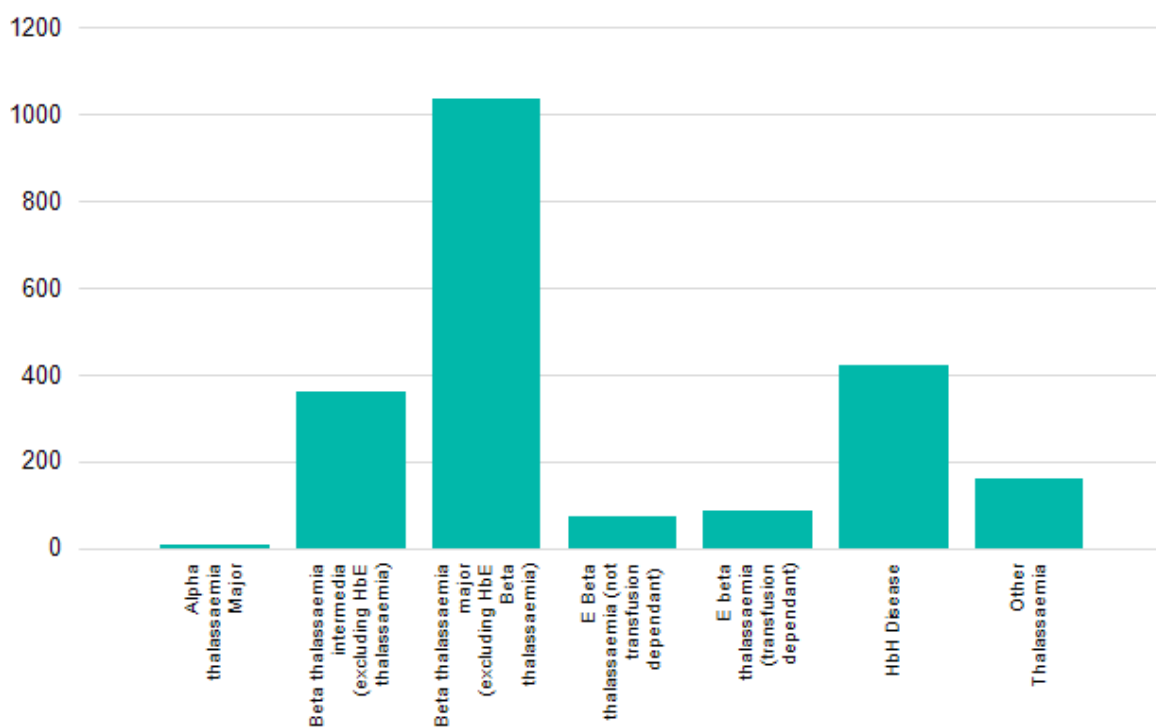


Figure 7 - Thalassaemia patients by diagnosis type.

Thalassaemia patients by ethnicity

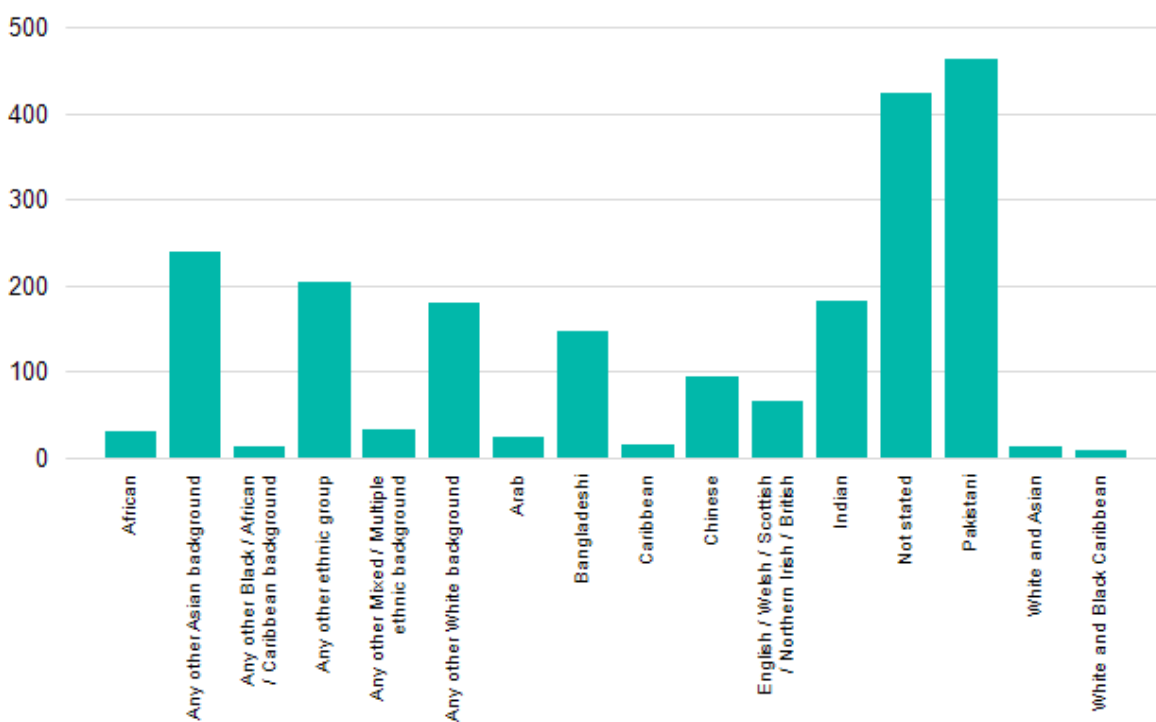


Figure 8 - Thalassaemia Patients by ethnicity.

HCC Name	Registrations
London, South Central and South West	904
Midlands	448
North	432
London and South East	330
South East London and South East	5
North Central London and East Anglia	<5
North East and Yorkshire	<5
North West	<5
South West	<5
West London	<5
West Midlands	<5
No HCC specified	15

Table 7 - Thalassaemia registrations by HCC.

Thalassaemia patients by age group

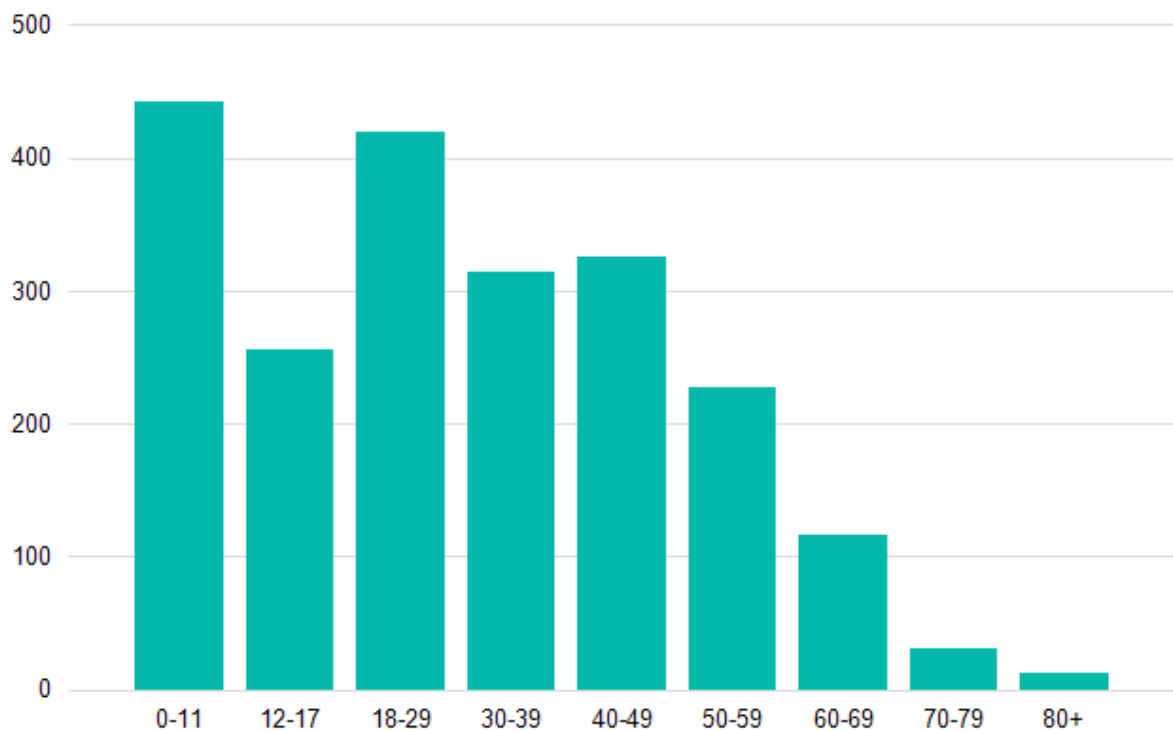


Figure 9 - Thalassaemia patients by age group.

Thalassaemia patients by treatment type (excluding other therapy)

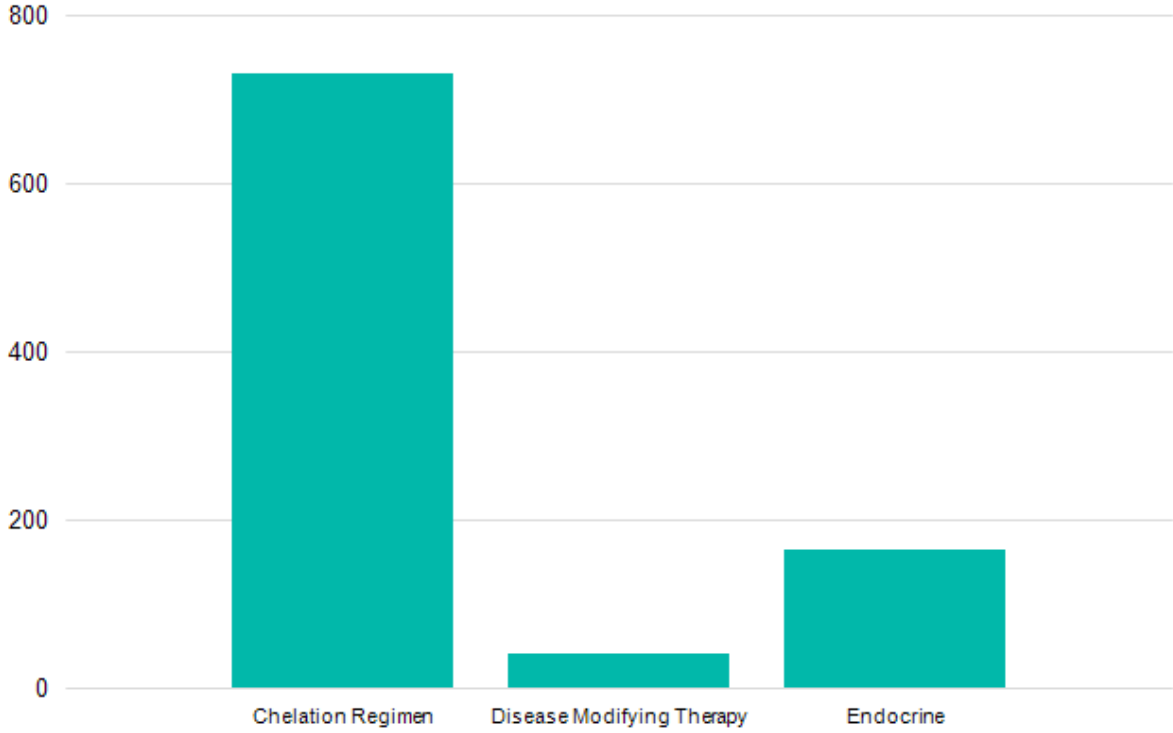


Figure 10 - Thalassaemia patients by treatment type (excluding other therapy).

Treatment type	Treatment	No.
Chelation Regimen	Deferasirox	444
	Desferrioxamine	118
	Deferiprone	68
	Deferasirox and Desferrioxamine	34
	Desferrioxamine and Deferiprone	34
	Deferasirox and Deferiprone	32
	Disease Modifying Therapy	Hydroxycarbamide
	Other	5
Endocrine	Levothyroxine	54
	Testosterone replacement therapy	42
	Insulin	35
	Oestrogen and progesterone replacement therapy	15
	Growth hormone	11
	Calcitriol (rocaltriol)	<5
	Hydrocortisone	<5
	Oral hypoglycaemic agent	<5
	Other Therapy	Other
	Folic acid	412
	Vitamin D	403
	Penicillin	135
	Warfarin	15
	Bisphosphonate	10
	NOAC/DOAC	8
	Sildenafil	6
	Penicillin alternative	5
	Ace inhibitor	<5
	Opioid therapy	<5
	Pancreatic enzyme supplement	<5

Table 8 - Thalassaemia patients by treatment type and treatment.

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

Thalassaemia patients regular transfusions

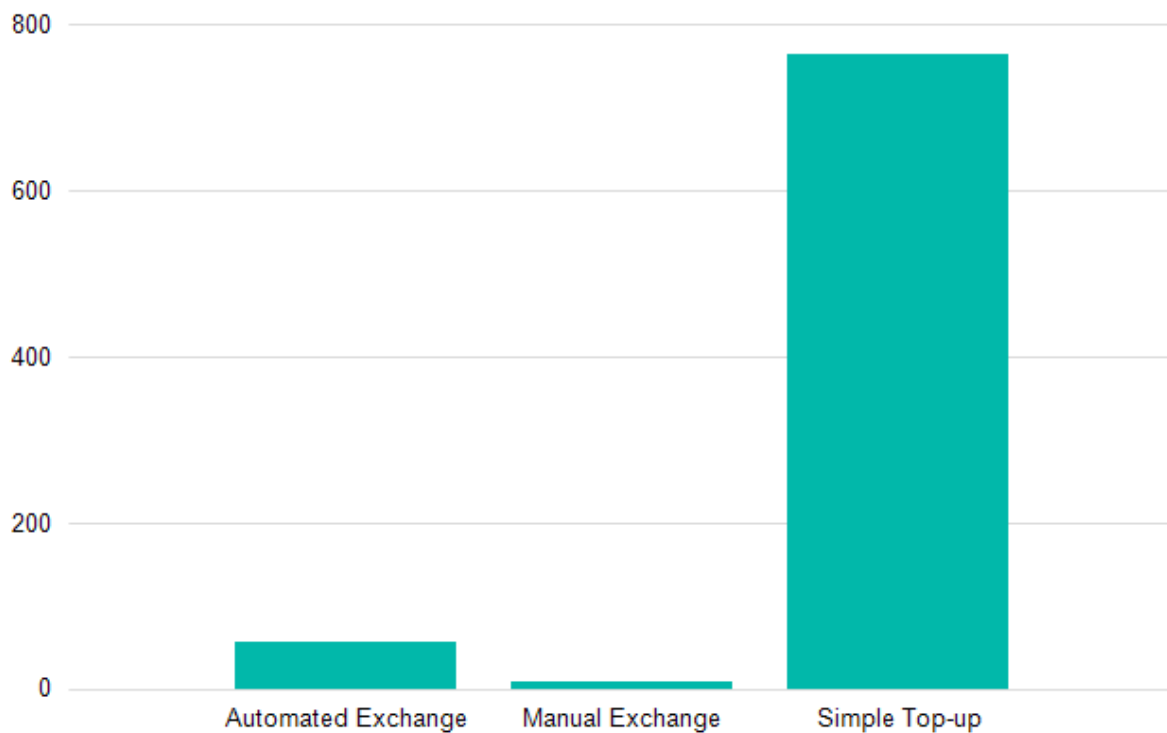


Figure 11 - Thalassaemia patients receiving regular transfusions by modality.

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

Chapter 4: Rare Inherited Anaemia Reports

SHT Name	Registrations
Birmingham Women's and Children's Hospital NHS FT and Sandwell and West Birmingham Hospitals NHS Trust	96
Manchester University NHS Foundation Trust	82
University College London Hospitals NHS Foundation Trust	76
London Northwest University Healthcare NHS Trust	61
Oxford University Hospitals NHS Foundation Trust	38
Nottingham University Hospitals NHS Trust	33
The Newcastle Upon Tyne Hospitals NHS Foundation Trust	32
Leeds Teaching Hospitals NHS Trust	26
Barts Health NHS Trust	25
University Hospitals Bristol & Weston NHS Foundation Trust	23
Royal Liverpool University Hospital (Liverpool University Hospitals NHS Foundation Trust)	22
Sheffield Teaching Hospitals NHS Foundation Trust	16
University Hospitals of Leicester NHS Trust	16
Whittington Health NHS Trust	15
Guy's and St Thomas' NHS Foundation Trust	13
Lewisham and Greenwich NHS Trust	13
Imperial College Healthcare NHS Trust	9
King's College Hospital NHS Foundation Trust	9
University Hospital of Wales (Cardiff and Vale University Health Board)	9
Homerton Healthcare NHS Foundation Trust	7
St Georges Healthcare NHS Foundation Trust	7
Croydon Health Services NHS Trust	6
Sheffield Children's NHS Foundation Trust	6
University Hospital Southampton NHS Foundation Trust	6
Addenbrooke's Hospital Cambridge (Cambridge University Hospitals NHS Foundation Trust)	<5
North Middlesex University Hospital NHS Trust	<5
No SHT specified	68

Table 9 - Rare Inherited Anaemia registrations by SHT.

Rare inherited anaemia patients by diagnosis type

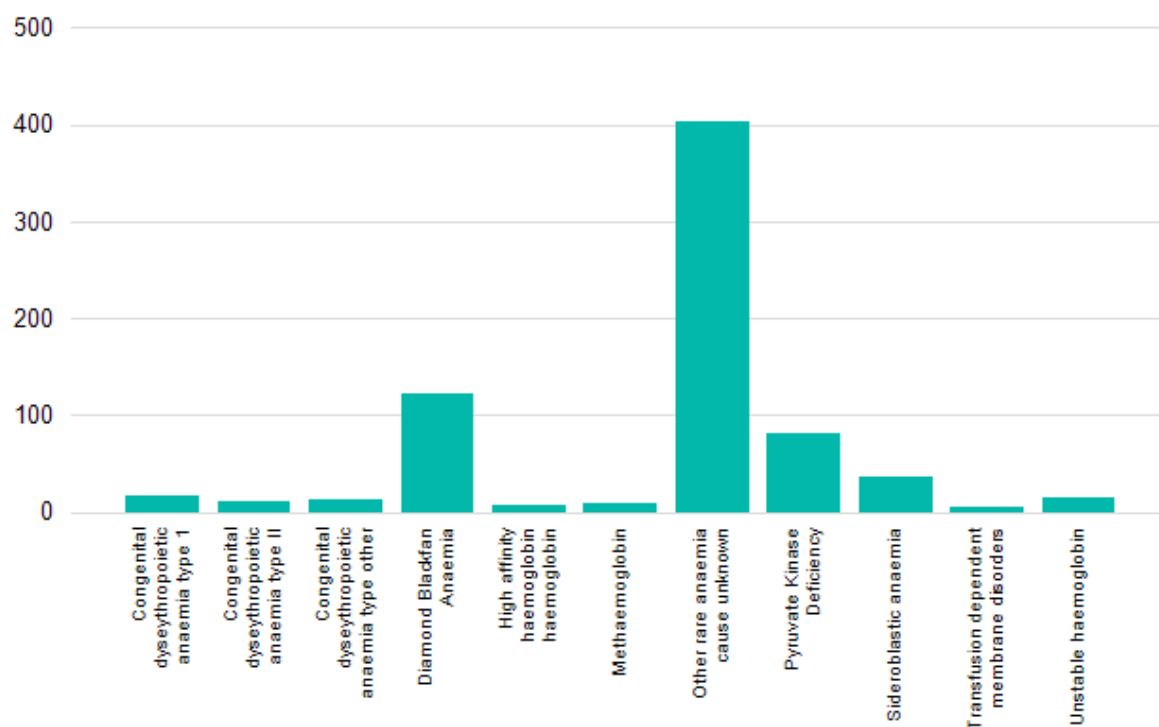


Figure 12 - Rare Inherited Anaemia patients by diagnosis type.

Rare inherited anaemia patients by ethnicity

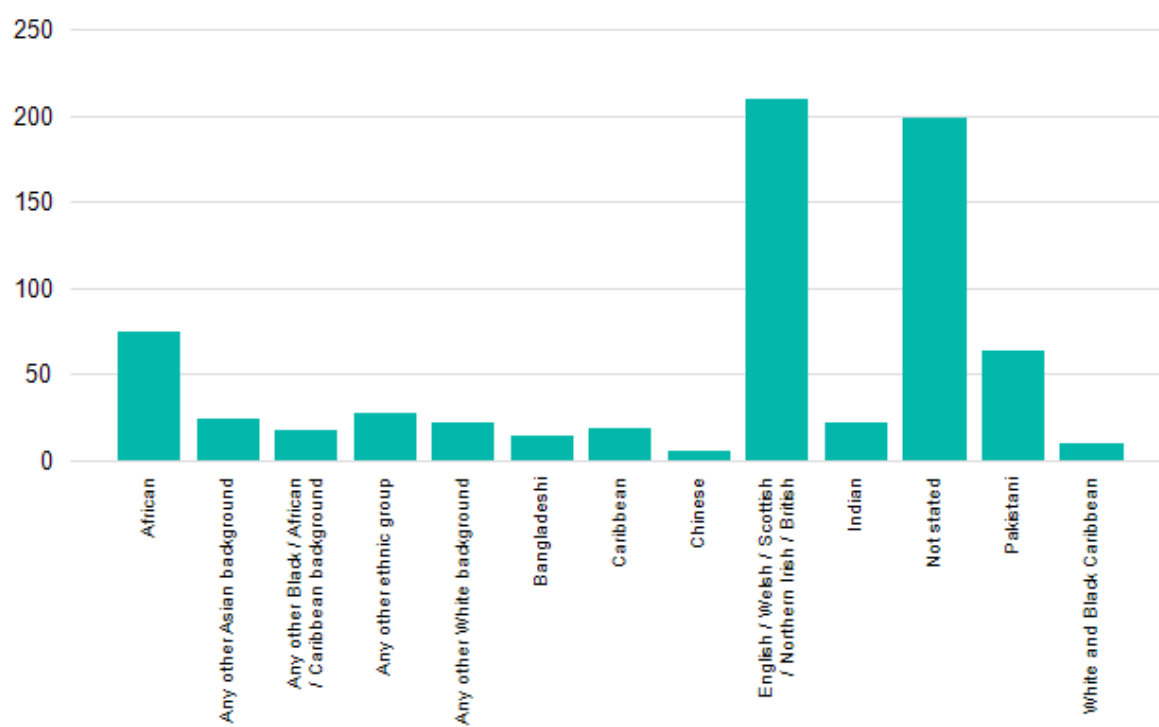


Figure 13 - Rare Inherited Anaemia patients by ethnicity.

HCC Name	Registrations
London, South Central and South West	245
North	181
Midlands	143
London and South East	59
South East London and South East	17
East London and Essex	<5
North East and Yorkshire	<5
North West	<5
West London	<5
West Midlands	<5
No HCC specified	65

Table 10 - Rare Inherited Anaemia registrations by HCC.

Rare inherited anaemia patients by age group

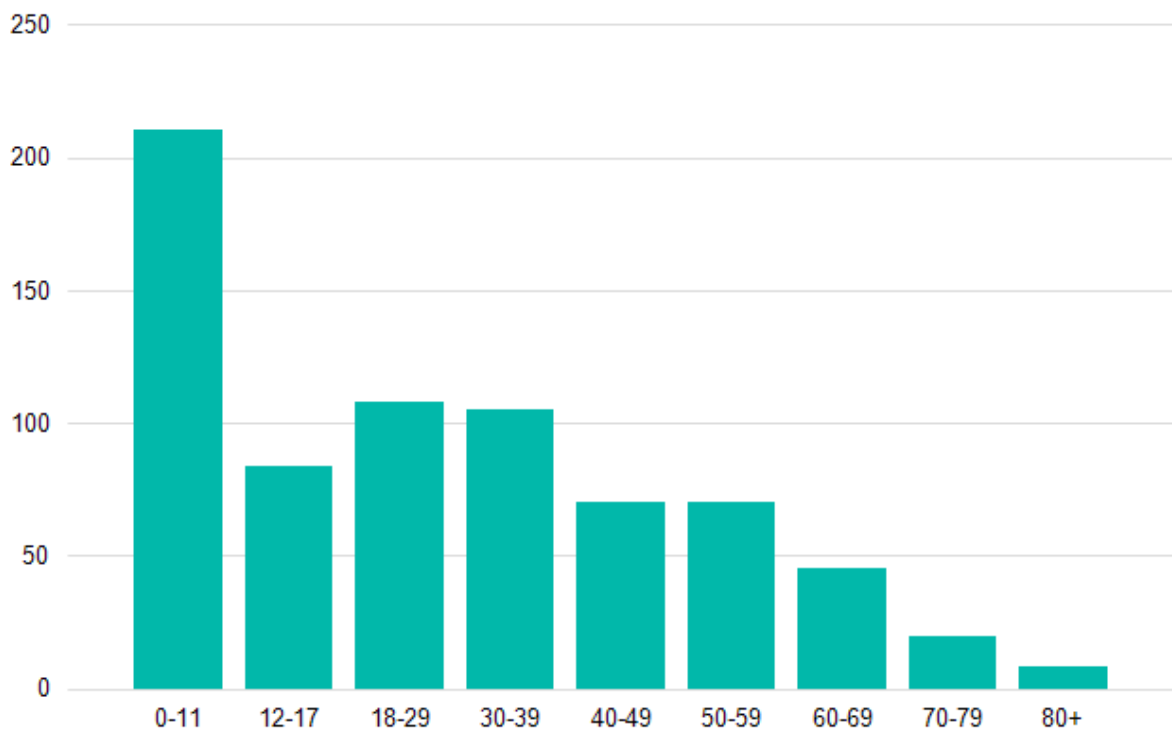


Figure 14 - Rare Inherited Anaemia patients by age group.

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

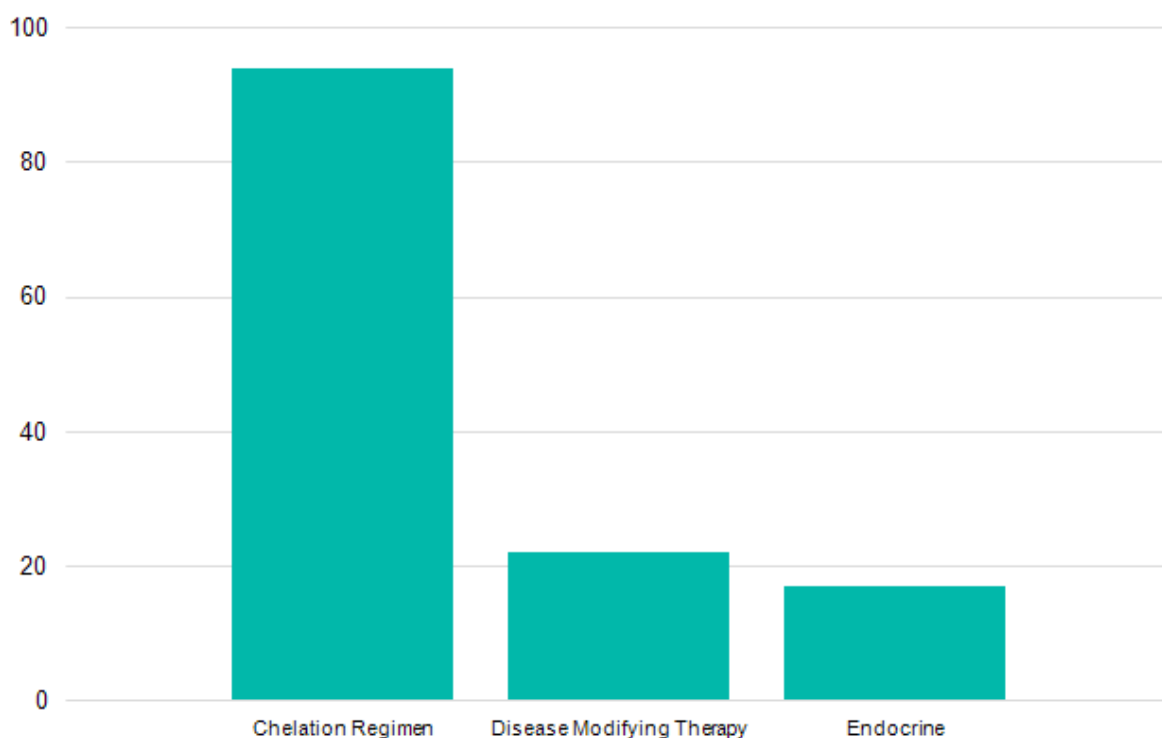


Figure 15 - Rare Inherited Anaemia patients by treatment type (excluding other therapy).

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

Treatment type	Treatment	No.
Chelation Regimen	Deferasirox	64
	Desferrioxamine	16
	Deferiprone	6
	Deferasirox and Deferiprone	<5
	Deferasirox and Desferrioxamine	<5
	Desferrioxamina and Deferiprone	<5
	Disease Modifying Therapy	Prednisolone
	Hydroxycarbamide	9
	Interferon	<5
Endocrine	Levothyroxine	9
	Growth hormone	<5
	Insulin	<5
	Testosterone replacement therapy	<5
	Other Therapy	Other
	Folic acid	117
	Vitamin D	66
	Penicillin	41
	Bisphosponate	<5
	Home oxygen	<5
	NOAC/DOAC	<5
	Penicillin alternative	<5
	Warfarin	<5

Table 11 - Rare Inherited Anaemia patients by treatment type and treatment.

Rare inherited anaemia patients regular transfusions

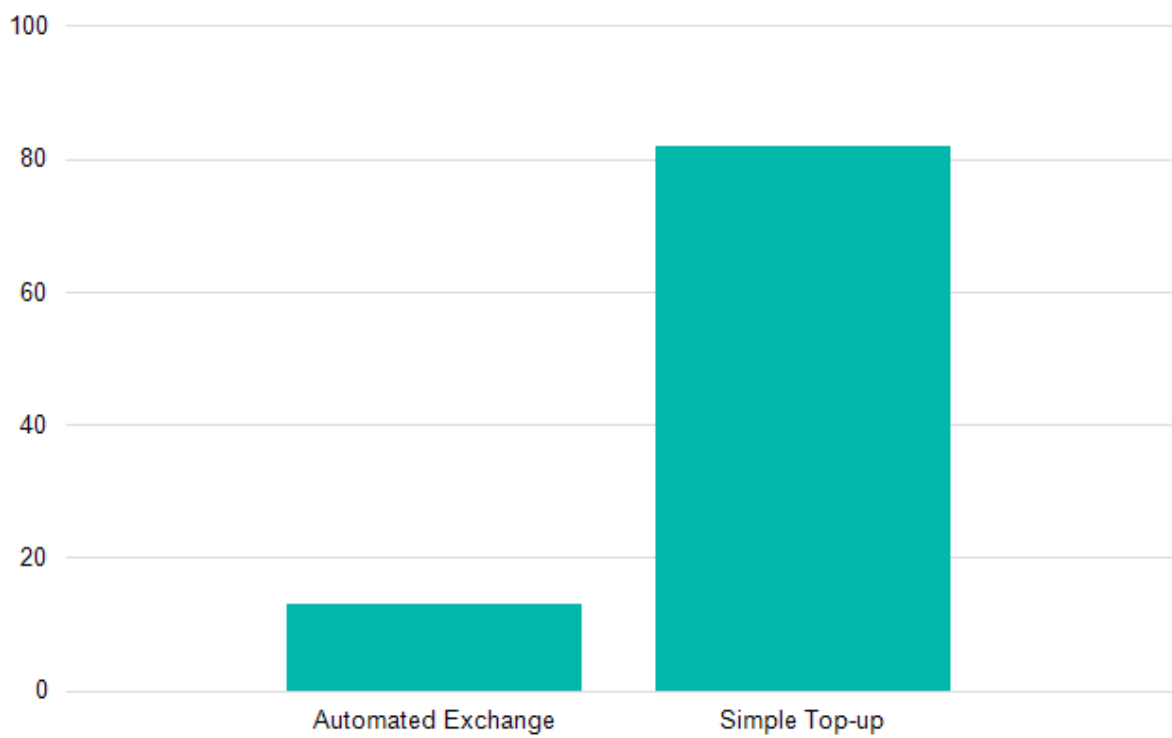


Figure 16 - Rare Inherited Anaemia patients with regular transfusions by modality.

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

Chapter 5: Reported Serious Events and Comorbidities.

Serious adverse events	No.
Death	32
Delayed HTR - Not thought to be associated with antibody: hyperhaemolysis	10
Ischaemic stroke	8
Cardiac failure	6
Delayed HTR - Associated with a new antibody (conventional DHTR)	<5
Delayed HTR - Associated with previous antibody	<5
Haemorrhagic stroke	<5
Intrauterine death	<5
Pneumococcal Infection	<5

Table 12 - Sickle Cell serious adverse events.

Comorbidity type	Comorbidity	No.
Acute Haemolytic Transfusion Reaction (HTR Acute)	Acute HTR - Not thought to be associated with antibody: hyperhaemolysis	9
	Acute HTR - Associated with a new antibody (conventional DHTR)	<5
Bacterial infection	Bacterial infectious disease (Other)	20
Cardiorespiratory	Acute chest syndrome	125
	Pneumonia	16
	Pulmonary embolism	7
	Fat embolism syndrome	6
	Deep vein thrombosis	5
	Asthma	<5
	Obstructive lung disease	<5
	Pulmonary hypertension	<5
Endocrine	Other endocrine complication	<5
Genitourinary	Priapism	15
	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
	Papillary necrosis	<5
Haematological	Simple painful crisis	851
	Acute haemolytic event not related to blood transfusion	<5

Hepatobiliary	Acute Pancreatitis	<5
	Ascending cholangitis	<5
	Cirrhosis of liver	<5
	Hepatic sequestration	<5
	Liver failure	<5
Neurological disorders	Chronic pain	12
	Epilepsy	<5
	Retinopathy Stage I Peripheral arterial occlusion	<5
	Retinopathy Stage II Peripheral arteriovenous anastomoses (hairpin loop)	<5
	Retinopathy Stage III Neovascular and fibrous proliferations (sea fan)	<5
	Retinopathy Stage IV Vitreous haemorrhage	<5
	Seizure without diagnosis of epilepsy	<5
	Silent cerebral infarcts	<5
	Visual loss	<5
	Obstetric/ gynaecological	Recurrent miscarriage
Orthopaedic	Avascular necrosis	20
	Leg ulcers	12
	Acute Osteomyelitis	11
	Chronic Osteomyelitis	<5
	Fracture	<5
	Osteopenia	<5
Other	Other complication not listed above	127
	Splenic sequestration	14
	Cancer	<5
Viral infection	Covid 19	94
	Influenza	19
	Other viral illness	15
	Hepatitis B	<5
	Parvovirus	<5

Table 13 - Sickle Cell comorbidities.

Serious adverse events	No.
Cardiac failure	<5
Delayed HTR - Not thought to be associated with antibody: hyperhaemolysis	<5

Table 14 - Thalassaemia serious adverse events.

Comorbidity type	Comorbidity	No.
Bacterial infection	Bacterial infectious disease (Other)	<5
Cardiorespiratory	Deep vein thrombosis	<5
	Pneumonia	<5
Endocrine	Insulin dependent diabetes	<5
Genitourinary	Hydronephrosis	<5
	Renal replacement therapy	<5
	Renal stones	<5
Haematological	Simple painful crisis	<5
Orthopaedic	Fracture	<5
	Osteopenia	<5
	Osteoporosis	<5
Other	Other complication not listed above	16
	Cancer	<5
Viral infection	Covid 19	9
	Influenza	<5
	Other viral illness	<5
	Parvovirus	<5

Table 15 - Thalassaemia comorbidities.

Serious adverse events	No.
Cardiac failure	<5
Death	<5

Table 16 - Rare Inherited Anaemia serious adverse events.

Comorbidity type	Comorbidity	No.
Bacterial infection	Bacterial infectious disease (Other)	<5
Cardiorespiratory	Pneumonia	<5
Endocrine	Adrenal insufficiency	<5
Haematological	Neutropenia	<5
	Simple painful crisis	<5
Orthopaedic	Osteopenia	<5
	Osteoporosis	<5
Other	Other complication not listed above	<5
Viral infection	Covid 19	<5
	Influenza	<5

Table 17 - Rare Inherited Anaemia comorbidities.