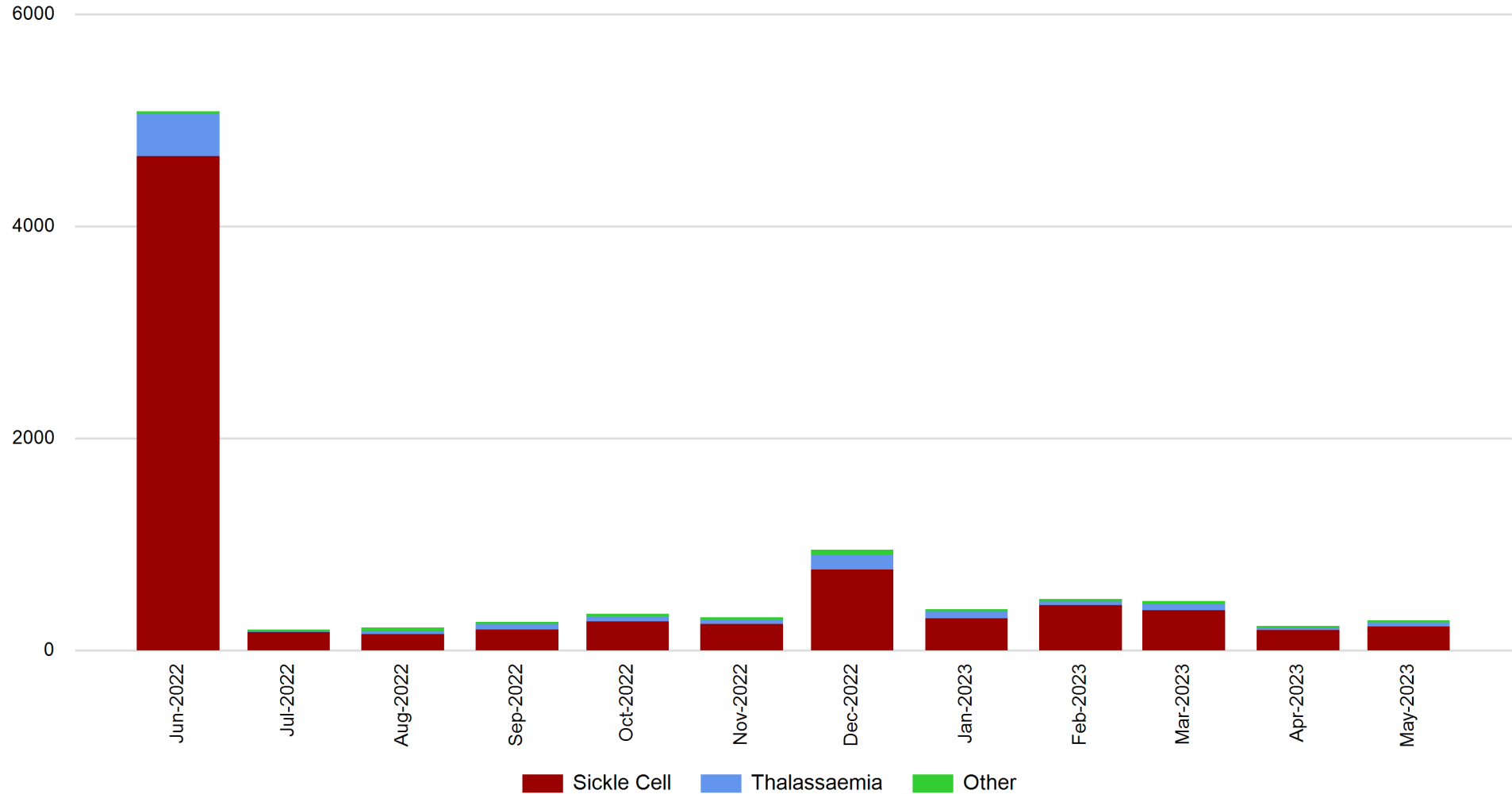


NHR - Monthly status report - June 2023.

Showing data entered for active patients in the last 12 months up to 31/05/2023.



New patient registrations by month and primary diagnosis.



NHR - Monthly status report - June 2023.



Showing data entered for active patients in the last 12 months up to 31/05/2023.

New and cumulative patient registrations by month and primary diagnosis.

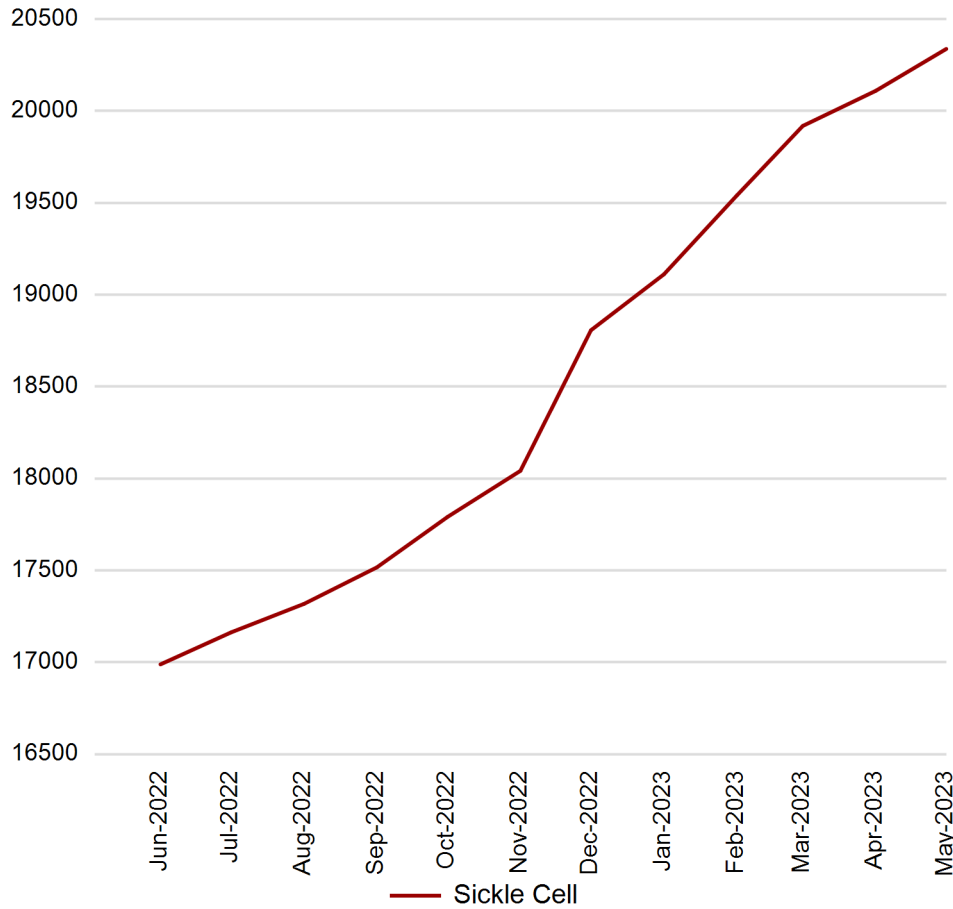
Month	Active patients registered			Cumulative active patients		
	Sickle Cell	Thalassaemia	Other	Sickle Cell	Thalassaemia	Other
Jun-2022	4,664	395	28	16,989	2,592	582
Jul-2022	174	7	15	17,163	2,599	597
Aug-2022	155	25	37	17,318	2,624	634
Sep-2022	199	50	19	17,517	2,674	653
Oct-2022	274	49	22	17,791	2,723	675
Nov-2022	251	39	21	18,042	2,762	696
Dec-2022	765	136	49	18,807	2,898	745
Jan-2023	304	68	17	19,111	2,966	762
Feb-2023	429	34	25	19,540	3,000	787
Mar-2023	378	58	29	19,918	3,058	816
Apr-2023	191	22	20	20,109	3,080	836
May-2023	228	36	21	20,337	3,116	857

NHR - Monthly status report - June 2023.

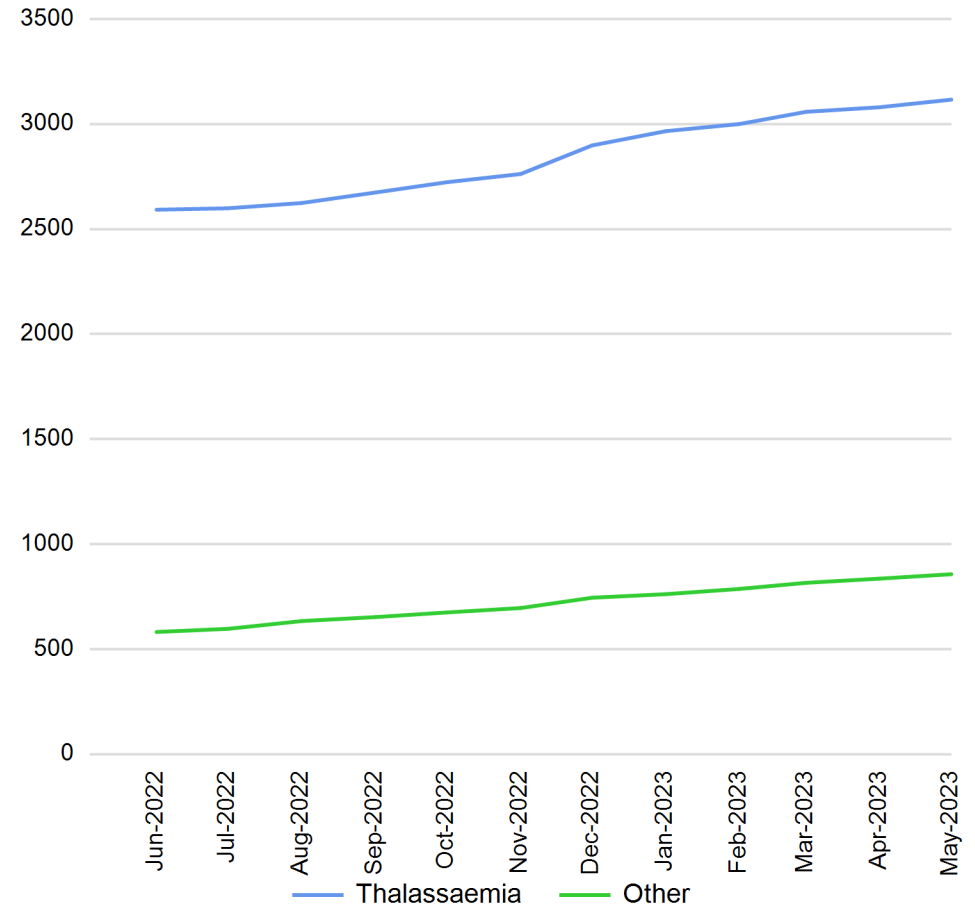
Showing data entered for active patients in the last 12 months up to 31/05/2023.



Total active registrations for patients diagnosed with sickle cell - from 01-Jun-2022.



Total active registrations for patients diagnosed with thalassaemia or another rare inherited anaemia (other) - from 01-Jun-2022.

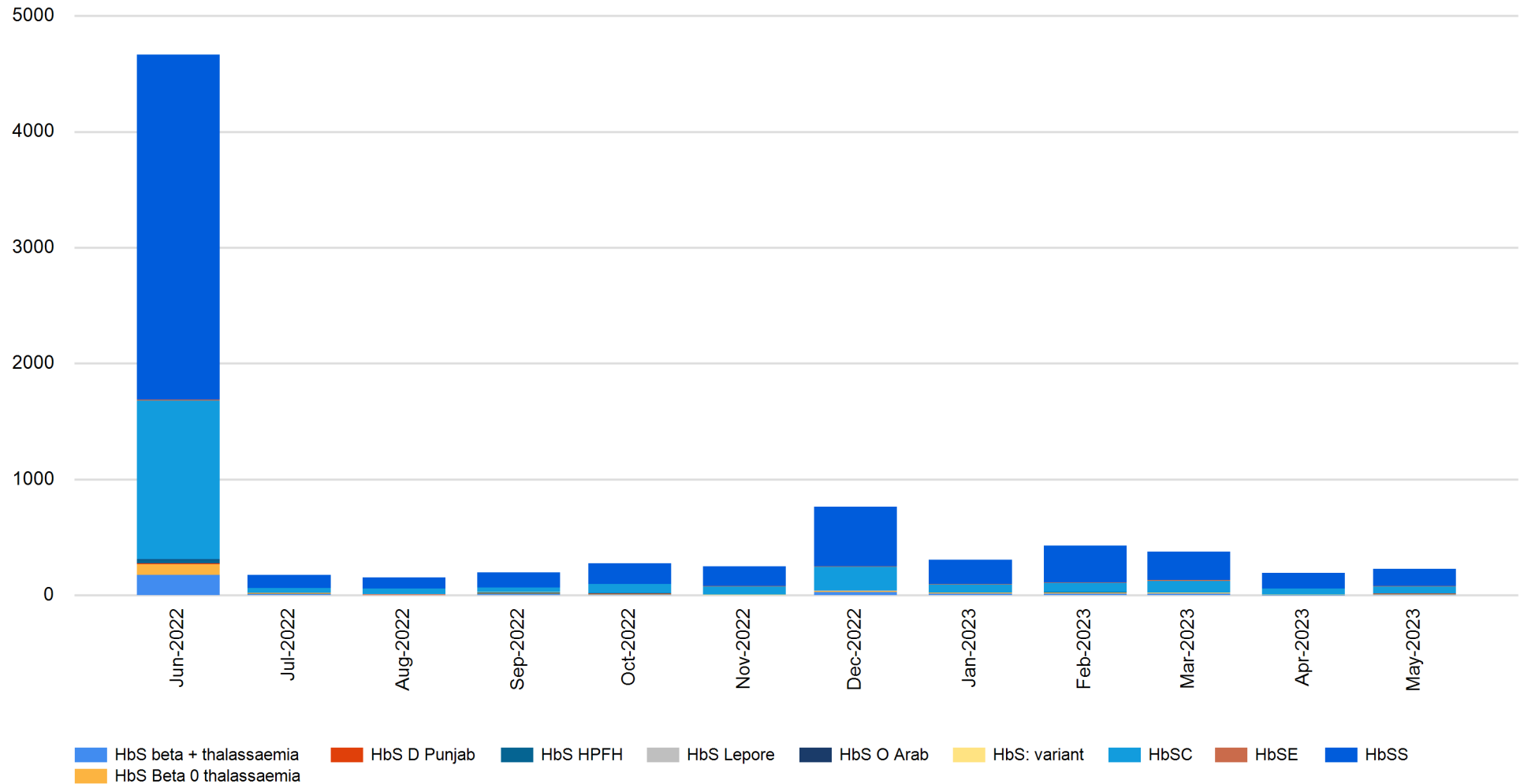


NHR - Monthly status report - June 2023.



Showing data entered for active patients in the last 12 months up to 31/05/2023.

New sickle cell patient registrations by month and secondary diagnosis.



NHR - Monthly status report - June 2023.



Showing data entered for active patients in the last 12 months up to 31/05/2023.

New and cumulative patient registrations diagnosed with sickle cell by month and secondary diagnosis.

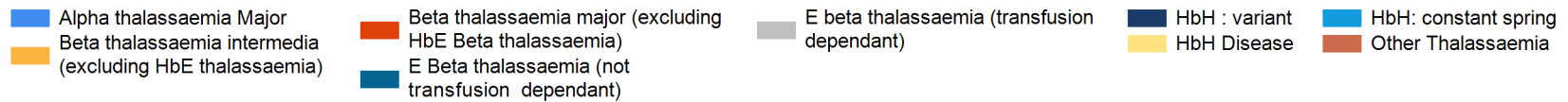
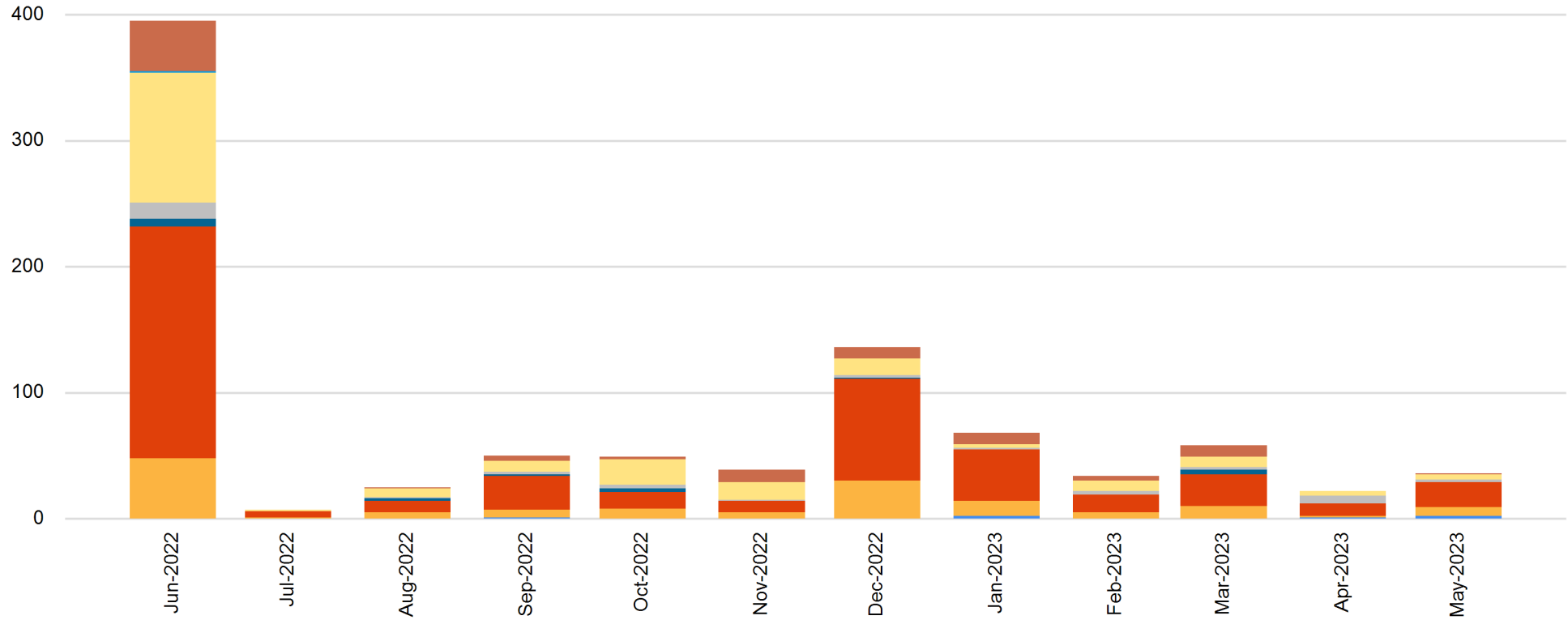
	Jun-2022	Jul-2022	Aug-2022	Sep-2022	Oct-2022	Nov-2022	Dec-2022	Jan-2023	Feb-2023	Mar-2023	Apr-2023	May-2023
Active patients registered												
Secondary diagnosis												
HbS beta + thalassaemia	177	12	4	10	6	4	25	12	13	15	3	6
HbS Beta 0 thalassaemia	88	4	1	6	8	1	11	9	8	6	2	5
HbS D Punjab	10	3	2	0	2	0	3	0	0	0	0	1
HbS HPFH	33	0	1	6	3	1	1	0	4	0	0	0
HbS Lepore	2	0	1	0	0	0	2	0	0	0	0	0
HbS O Arab	1	1	0	1	0	0	0	0	0	0	0	0
HbS: variant	0	1	0	2	0	1	0	0	0	3	1	0
HbSC	1,368	40	50	43	77	71	206	73	84	101	51	64
HbSE	9	0	0	0	0	1	1	2	3	5	0	2
HbSS	2,976	113	96	131	178	172	516	208	317	248	134	150
Cumulative active patients												
HbS beta + thalassaemia	682	694	698	708	714	718	743	755	768	783	786	792
HbS Beta 0 thalassaemia	334	338	339	345	353	354	365	374	382	388	390	395
HbS D Punjab	55	58	60	60	62	62	65	65	65	65	65	66
HbS HPFH	136	136	137	143	146	147	148	148	152	152	152	152
HbS Lepore	5	5	6	6	6	6	8	8	8	8	8	8
HbS O Arab	9	10	10	11	11	11	11	11	11	11	11	11
HbS: variant	16	17	17	19	19	20	20	20	20	23	24	24
HbSC	4,657	4,697	4,747	4,790	4,867	4,938	5,144	5,217	5,301	5,402	5,453	5,517
HbSE	36	36	36	36	36	37	38	40	43	48	48	50
HbSS	11,059	11,172	11,268	11,399	11,577	11,749	12,265	12,473	12,790	13,038	13,172	13,322

NHR - Monthly status report - June 2023.

Showing data entered for active patients in the last 12 months up to 31/05/2023.



New thalassaemia patient registrations by month and secondary diagnosis.



NHR - Monthly status report - June 2023.



Showing data entered for active patients in the last 12 months up to 31/05/2023.

New and cumulative patient registrations diagnosed with thalassaemia by month and secondary diagnosis.

	Jun-2022	Jul-2022	Aug-2022	Sep-2022	Oct-2022	Nov-2022	Dec-2022	Jan-2023	Feb-2023	Mar-2023	Apr-2023	May-2023
Active patients registered												
Secondary diagnosis												
Alpha thalassaemia Major	0	0	0	1	0	0	0	2	0	0	1	2
Beta thalassaemia intermedia (excluding HbE thalassaemia)	48	1	5	6	8	5	30	12	5	10	1	7
Beta thalassaemia major (excluding HbE Beta thalassaemia)	184	5	9	27	13	9	81	41	14	25	10	20
E Beta thalassaemia (not transfusion dependant)	6	0	2	1	3	0	1	0	0	4	0	0
E beta thalassaemia (transfusion dependant)	13	0	1	2	3	1	2	1	3	2	6	2
HbH : variant	0	0	0	0	0	0	0	0	0	0	0	0
HbH Disease	103	1	7	9	20	14	13	3	8	8	4	4
HbH: constant spring	1	0	0	0	0	0	0	0	0	0	0	0
Other Thalassaemia	40	0	1	4	2	10	9	9	4	9	0	1
Cumulative active patients												
Alpha thalassaemia Major	0	0	0	1	1	1	1	3	3	3	4	6
Beta thalassaemia intermedia (excluding HbE thalassaemia)	416	417	422	428	436	441	471	483	488	498	499	506
Beta thalassaemia major (excluding HbE Beta thalassaemia)	1,370	1,375	1,384	1,411	1,424	1,433	1,514	1,555	1,569	1,594	1,604	1,624
E Beta thalassaemia (not transfusion dependant)	66	66	68	69	72	72	73	73	73	77	77	77
E beta thalassaemia (transfusion dependant)	93	93	94	96	99	100	102	103	106	108	114	116
HbH : variant	3	3	3	3	3	3	3	3	3	3	3	3
HbH Disease	458	459	466	475	495	509	522	525	533	541	545	549
HbH: constant spring	3	3	3	3	3	3	3	3	3	3	3	3
Other Thalassaemia	183	183	184	188	190	200	209	218	222	231	231	232

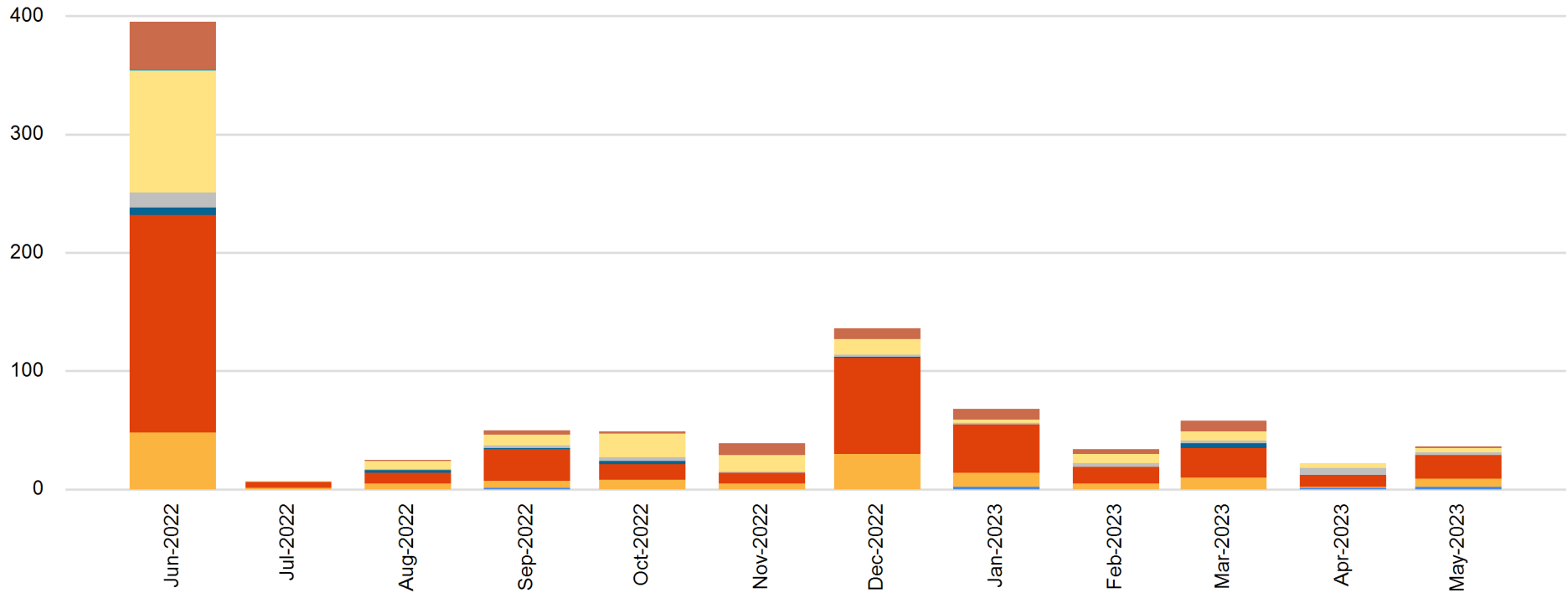


NHR - Monthly status report - June 2023.

Showing data entered for active patients in the last 12 months up to 31/05/2023.



New patient registrations diagnosed with another rare inherited anaemia (other) by month and secondary diagnosis.



- Alpha thalassaemia Major
- Beta thalassaemia intermedia (excluding HbE thalassaemia)
- Beta thalassaemia major (excluding HbE Beta thalassaemia)
- E Beta thalassaemia (not transfusion dependant)
- E beta thalassaemia (transfusion dependant)
- HbH : variant
- HbH Disease
- HbH: constant spring
- Other Thalassaemia



NHR - Monthly status report - June 2023.



Showing data entered for active patients in the last 12 months up to 31/05/2023.

New and cumulative patient registrations diagnosed with another rare inherited anaemia (other) by month and secondary diagnosis.

	Jun-2022	Jul-2022	Aug-2022	Sep-2022	Oct-2022	Nov-2022	Dec-2022	Jan-2023	Feb-2023	Mar-2023	Apr-2023	May-2023
Active patients registered												
ADA 2	0	0	0	0	0	0	0	0	0	0	0	0
Congenital dyseythropoietic anaemia type 1	1	1	0	1	0	0	0	0	0	0	0	0
Congenital dyseythropoietic anaemia type II	0	0	0	0	2	0	3	1	0	0	0	0
Congenital dyseythropoietic anaemia type III	0	0	0	0	0	0	0	0	0	0	0	0
Congenital dyseythropoietic anaemia type IV	0	0	0	0	0	0	0	0	0	0	0	0
Congenital dyseythropoietic anaemia type other	0	2	0	0	0	2	1	0	0	1	0	0
Congenital dyseythropoietic anaemia type VI	0	0	0	0	0	0	0	0	0	0	0	0
Diamond Blackfan Anaemia	8	6	5	4	6	5	5	4	7	5	2	5
Glucose Phosphate Isomerase Deficiency	0	0	0	0	0	0	0	0	0	0	0	0
Hexokinase Deficiency	0	0	0	0	0	0	0	0	0	0	0	0
High affinity haemoglobin haemoglobin	1	0	1	0	0	0	1	0	0	0	2	0
Methaemoglobin	1	1	1	0	0	0	2	1	0	0	0	0
Other rare anaemia cause unknown	11	5	25	12	9	14	28	10	14	20	11	14
Pyruvate Kinase Deficiency	4	0	3	1	2	0	5	1	3	1	0	0
Sideroblastic anaemia	2	0	2	0	2	0	2	0	1	2	2	2
Transfusion dependent membrane disorders	0	0	0	1	0	0	0	0	0	0	0	0
Unstable haemoglobin	0	0	0	0	1	0	2	0	0	0	3	0

NHR - Monthly status report - June 2023.



Showing data entered for active patients in the last 12 months up to 31/05/2023.

New and cumulative patient registrations diagnosed with another rare inherited anaemia (other) by month and secondary diagnosis.

	Jun-2022	Jul-2022	Aug-2022	Sep-2022	Oct-2022	Nov-2022	Dec-2022	Jan-2023	Feb-2023	Mar-2023	Apr-2023	May-2023
Cumulative patients registered												
ADA 2	0	0	0	0	0	0	0	0	0	0	0	0
Congenital dyseythropoietic anaemia type 1	14	15	15	16	16	16	16	16	16	16	16	16
Congenital dyseythropoietic anaemia type II	7	7	7	7	9	9	12	13	13	13	13	13
Congenital dyseythropoietic anaemia type III	2	2	2	2	2	2	2	2	2	2	2	2
Congenital dyseythropoietic anaemia type IV	1	1	1	1	1	1	1	1	1	1	1	1
Congenital dyseythropoietic anaemia type other	12	14	14	14	14	16	17	17	17	18	18	18
Congenital dyseythropoietic anaemia type VI	0	0	0	0	0	0	0	0	0	0	0	0
Diamond Blackfan Anaemia	119	125	130	134	140	145	150	154	161	166	168	173
Glucose Phosphate Isomerase Deficiency	2	2	2	2	2	2	2	2	2	2	2	2
Hexokinase Deficiency	0	0	0	0	0	0	0	0	0	0	0	0
High affinity haemoglobin haemoglobin	4	4	5	5	5	5	6	6	6	6	8	8
Methaemoglobin	6	7	8	8	8	8	10	11	11	11	11	11
Other rare anaemia cause unknown	280	285	310	322	331	345	373	383	397	417	428	442
Pyruvate Kinase Deficiency	82	82	85	86	88	88	93	94	97	98	98	98
Sideroblastic anaemia	33	33	35	35	37	37	39	39	40	42	44	46
Transfusion dependent membrane disorders	4	4	4	5	5	5	5	5	5	5	5	5
Unstable haemoglobin	16	16	16	16	17	17	19	19	19	19	22	22