

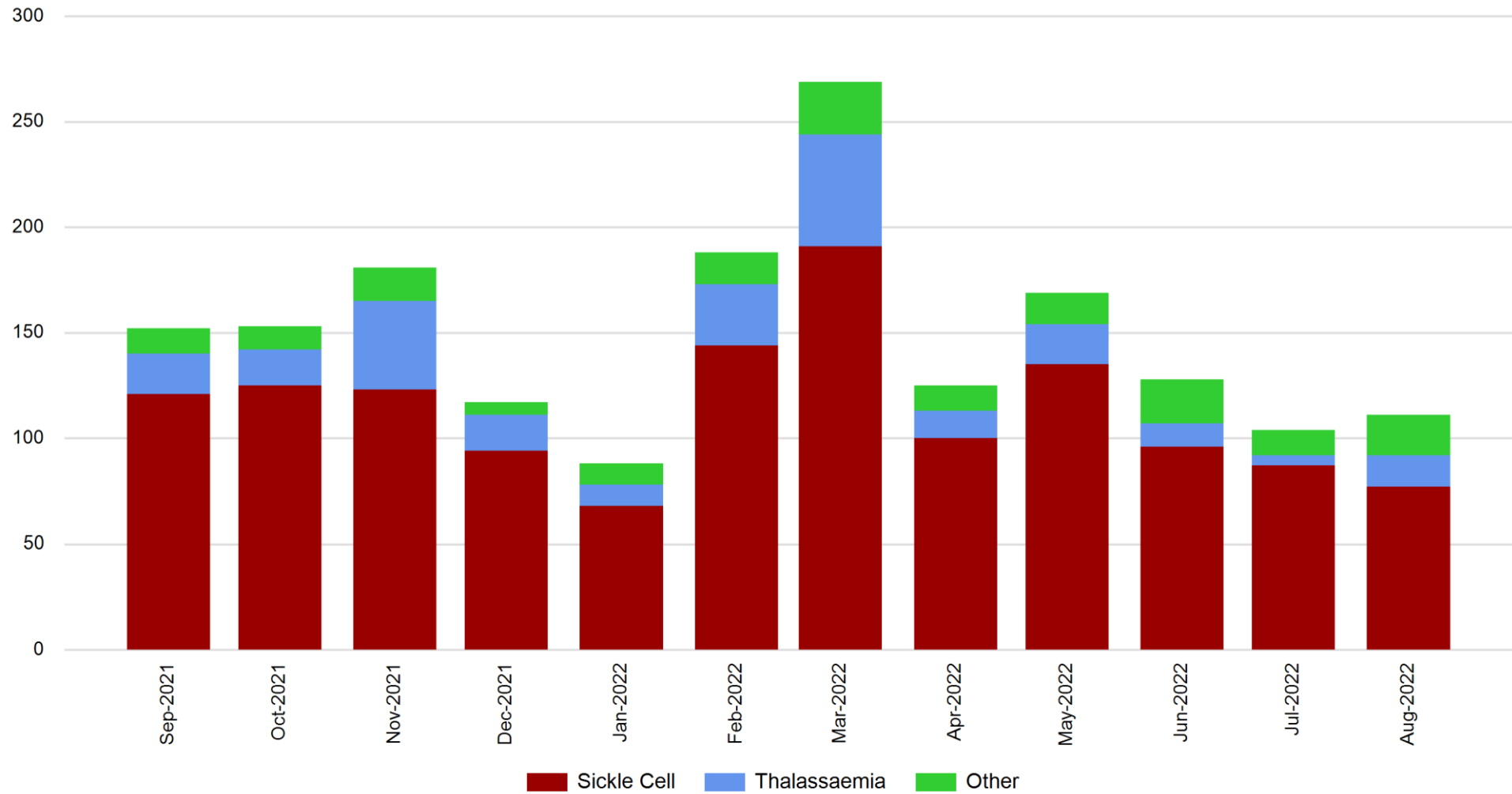
# NHR - Monthly status report - August 2022.



Showing data entered for active\* patients in the last 12 months up to 31/08/2022.

\*Active patient registrations on the NHR. Patients may be registered at more than one centre.

## New patient registrations by month and primary diagnosis.



# NHR - Monthly status report - August 2022.



Showing data entered for active\* patients in the last 12 months up to 31/08/2022.

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## 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
Sep-2021	121	19	12	13,586	1,938	560
Oct-2021	125	17	11	13,711	1,955	571
Nov-2021	123	42	16	13,834	1,997	587
Dec-2021	94	17	6	13,928	2,014	593
Jan-2022	68	10	10	13,996	2,024	603
Feb-2022	144	29	15	14,140	2,053	618
Mar-2022	191	53	25	14,331	2,106	643
Apr-2022	100	13	12	14,431	2,119	655
May-2022	135	19	15	14,566	2,138	670
Jun-2022	96	11	21	14,662	2,149	691
Jul-2022	87	5	12	14,749	2,154	703
Aug-2022	77	15	19	14,826	2,169	722

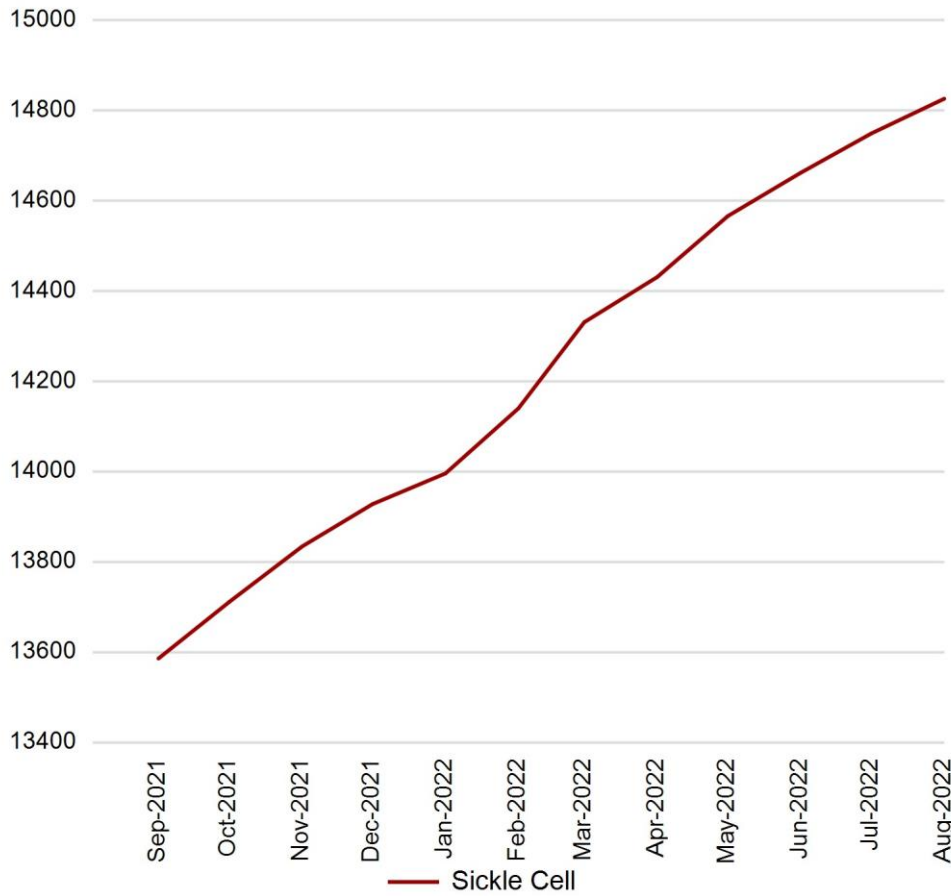
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Showing data entered for active\* patients in the last 12 months up to 31/08/2022.

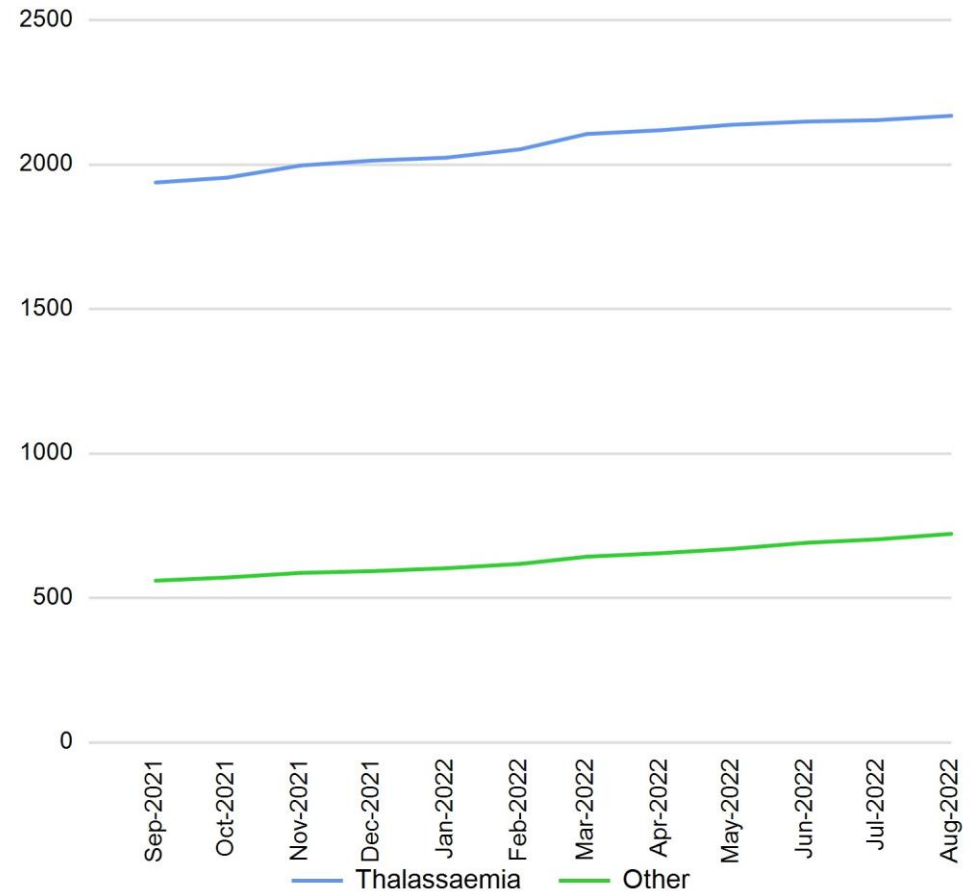
\*Active patient registrations on the NHR. Patients may be registered at more than one centre.



Total active registrations for patients diagnosed with sickle cell - from 01-Sep-2021.



Total active registrations for patients diagnosed with thalassaemia or another rare inherited anaemia (other) - from 01-Sep-2021.



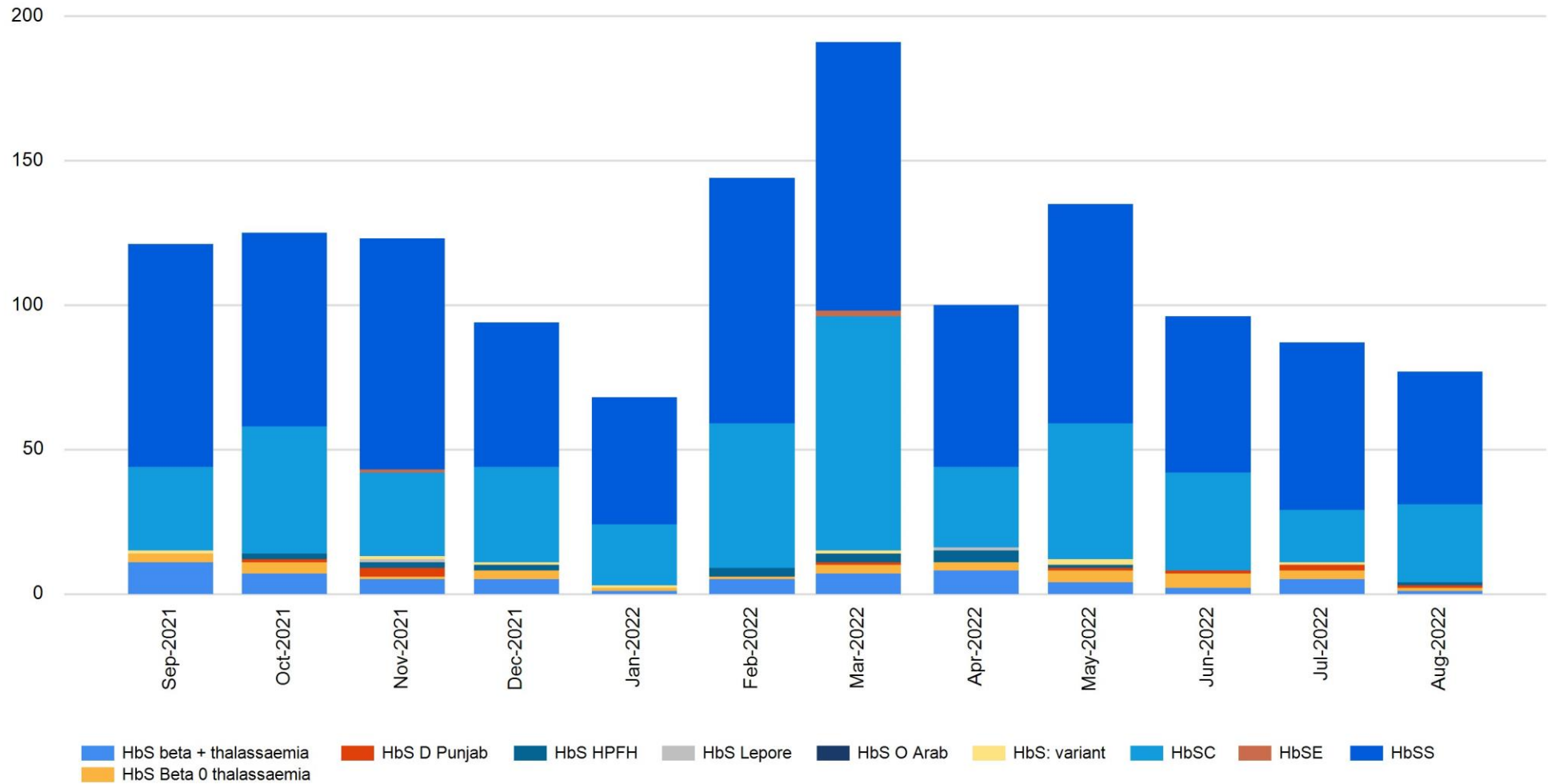
# NHR - Monthly status report - August 2022.

Showing data entered for active\* patients in the last 12 months up to 31/08/2022.

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## New sickle cell patient registrations by month and secondary diagnosis.



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



# NHR - Monthly status report - August 2022.



Showing data entered for active\* patients in the last 12 months up to 31/08/2022.

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		Sep-2021	Oct-2021	Nov-2021	Dec-2021	Jan-2022	Feb-2022	Mar-2022	Apr-2022	May-2022	Jun-2022	Jul-2022	Aug-2022
Secondary diagnosis													
Active patients registered	HbS beta + thalassaemia	11	7	5	5	1	5	7	8	4	2	5	1
	HbS Beta 0 thalassaemia	3	4	1	3	1	1	3	3	4	5	3	1
	HbS D Punjab	0	1	3	0	0	0	1	0	1	1	2	1
	HbS HPFH	0	2	2	2	0	3	3	4	1	0	0	1
	HbS Lepore	0	0	1	0	0	0	0	1	0	0	0	0
	HbS O Arab	0	0	0	0	0	0	0	0	0	0	0	0
	HbS: variant	1	0	1	1	1	0	1	0	2	0	1	0
	HbSC	29	44	29	33	21	50	81	28	47	34	18	27
	HbSE	0	0	1	0	0	0	2	0	0	0	0	0
HbSS	77	67	80	50	44	85	93	56	76	54	58	46	
Cumulative active patients	HbS beta + thalassaemia	554	561	566	571	572	577	584	592	596	598	603	604
	HbS Beta 0 thalassaemia	250	254	255	258	259	260	263	266	270	275	278	279
	HbS D Punjab	30	31	34	34	34	34	35	35	36	37	39	40
	HbS HPFH	118	120	122	124	124	127	130	134	135	135	135	136
	HbS Lepore	4	4	5	5	5	5	5	6	6	6	6	6
	HbS O Arab	7	7	7	7	7	7	7	7	7	7	7	7

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HbS: variant	13	13	14	15	16	16	17	17	19	19	20	20
HbSC	3,708	3,752	3,781	3,814	3,835	3,885	3,966	3,994	4,041	4,075	4,093	4,120
HbSE	32	32	33	33	33	33	35	35	35	35	35	35
HbSS	8,870	8,937	9,017	9,067	9,111	9,196	9,289	9,345	9,421	9,475	9,533	9,579

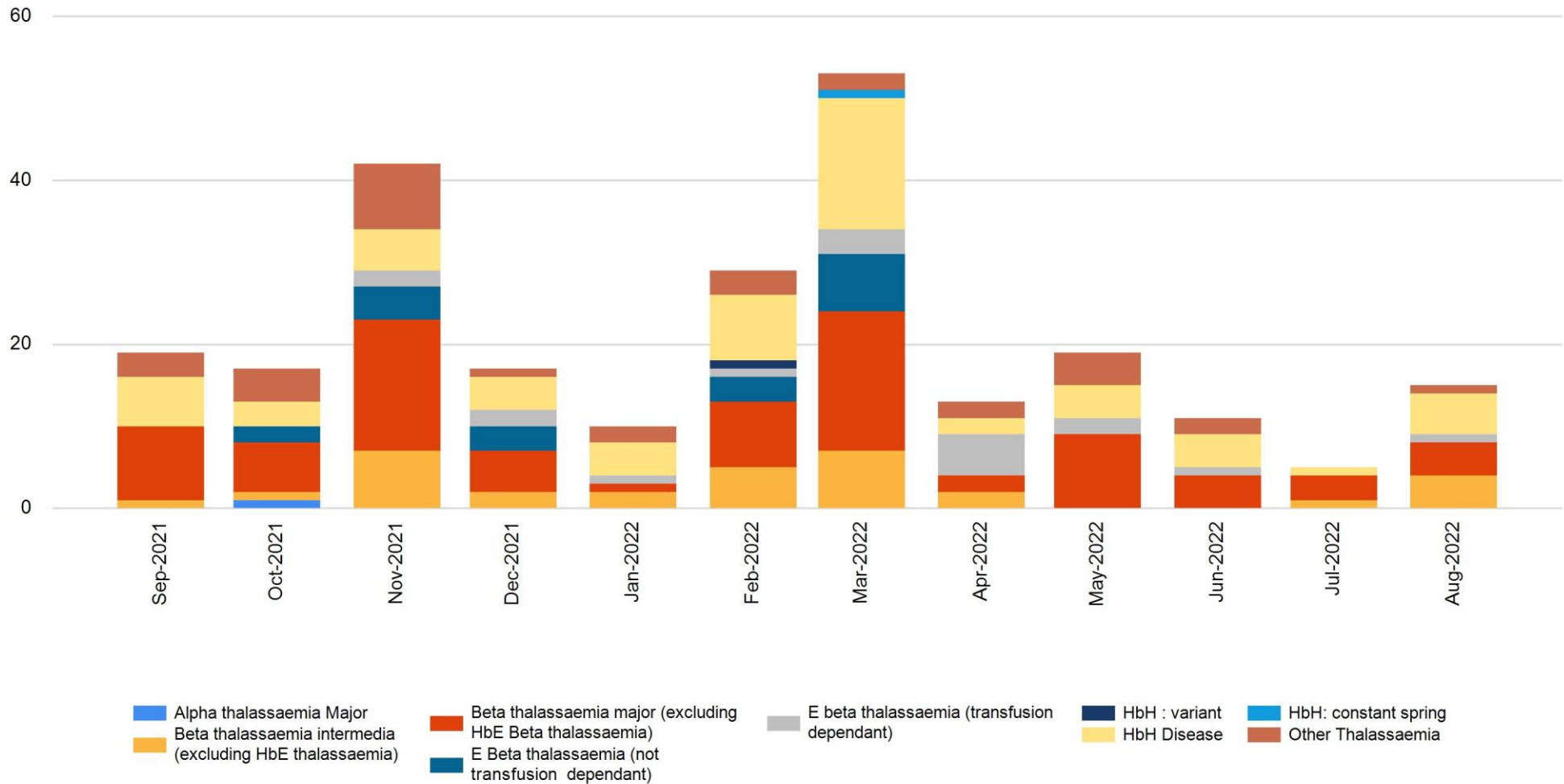
# NHR - Monthly status report - August 2022.



Showing data entered for active\* patients in the last 12 months up to 31/08/2022.

\*Active patient registrations on the NHR. Patients may be registered at more than one centre.

## New thalassaemia patient registrations by month and secondary diagnosis.



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



# NHR - Monthly status report - August 2022.



Showing data entered for active\* patients in the last 12 months up to 31/08/2022.

\*Active patient registrations on the NHR. Patients may be registered at more than one centre.

	Sep-2021	Oct-2021	Nov-2021	Dec-2021	Jan-2022	Feb-2022	Mar-2022	Apr-2022	May-2022	Jun-2022	Jul-2022	Aug-2022
<b>Active patients registered</b>												
Secondary diagnosis												
Alpha thalassaemia Major	0	1	0	0	0	0	0	0	0	0	0	0
Beta thalassaemia intermedia (excluding HbE thalassaemia)	1	1	7	2	2	5	7	2	0	0	1	4
Beta thalassaemia major (excluding HbE Beta thalassaemia)	9	6	16	5	1	8	17	2	9	4	3	4
E Beta thalassaemia (not transfusion dependant)	0	2	4	3	0	3	7	0	0	0	0	0
E beta thalassaemia (transfusion dependant)	0	0	2	2	1	1	3	5	2	1	0	1
HbH : variant	0	0	0	0	0	1	0	0	0	0	0	0
HbH Disease	6	3	5	4	4	8	16	2	4	4	1	5
HbH: constant spring	0	0	0	0	0	0	1	0	0	0	0	0
Other Thalassaemia	3	4	8	1	2	3	2	2	4	2	0	1
<b>Cumulative active patients</b>												
Alpha thalassaemia Major	1	2	2	2	2	2	2	2	2	2	2	2
Beta thalassaemia intermedia (excluding HbE thalassaemia)	320	321	328	330	332	337	344	346	346	346	347	351
Beta thalassaemia major (excluding HbE Beta thalassaemia)	1,078	1,084	1,100	1,105	1,106	1,114	1,131	1,133	1,142	1,146	1,149	1,153
E Beta thalassaemia (not transfusion dependant)	30	32	36	39	39	42	49	49	49	49	49	49
E beta thalassaemia (transfusion dependant)	51	51	53	55	56	57	60	65	67	68	68	69
HbH : variant	0	0	0	0	0	1	1	1	1	1	1	1



## NHR - Monthly status report - August 2022.



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HbH Disease	333	336	341	345	349	357	373	375	379	383	384	389
HbH: constant spring	1	1	1	1	1	1	2	2	2	2	2	2
Other Thalassaemia	124	128	136	137	139	142	144	146	150	152	152	153

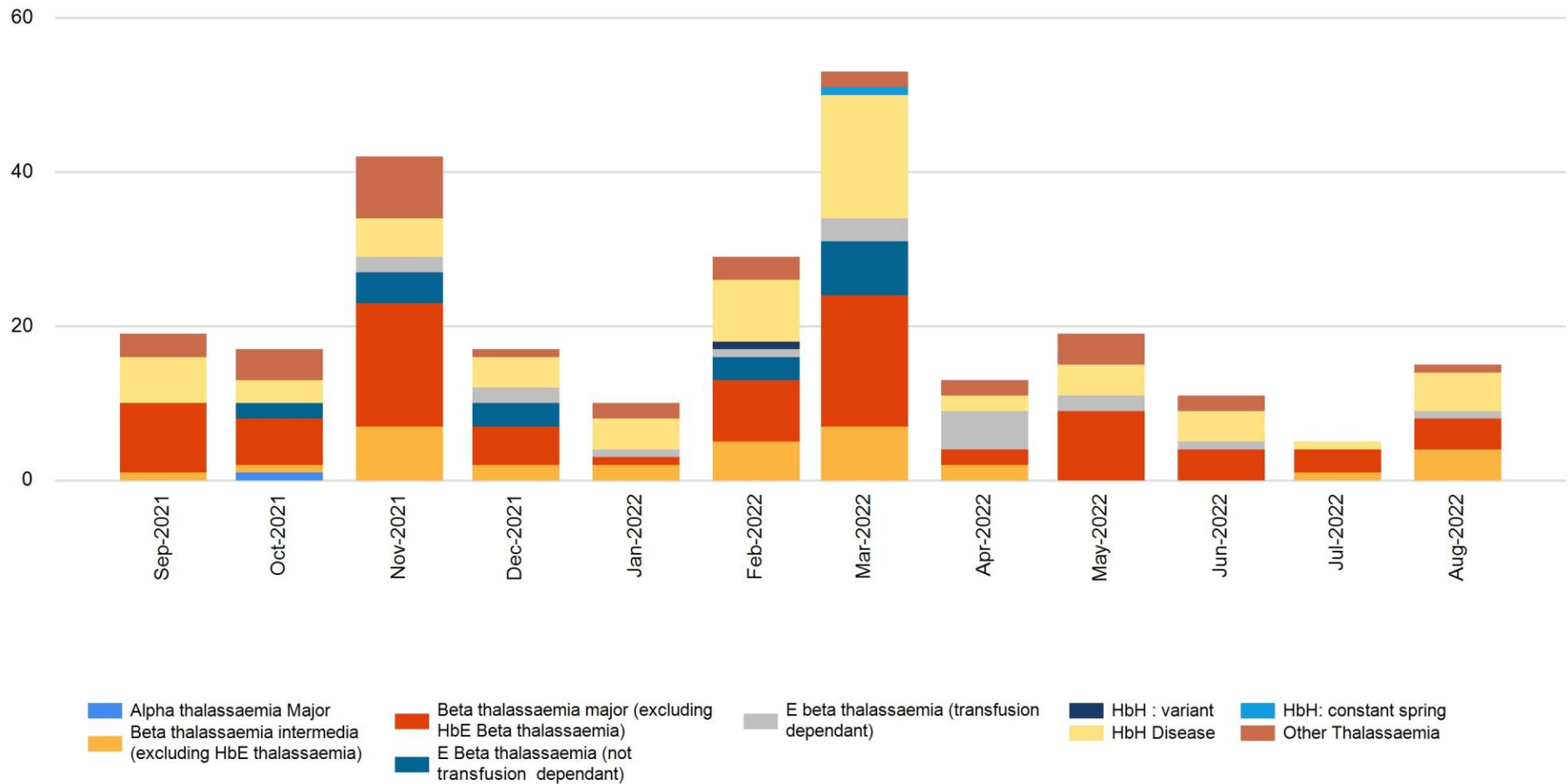
# NHR - Monthly status report - August 2022.

Showing data entered for active\* patients in the last 12 months up to 31/08/2022.

\*Active patient registrations on the NHR. Patients may be registered at more than one centre.



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



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



# NHR - Monthly status report - August 2022.



Showing data entered for active\* patients in the last 12 months up to 31/08/2022.

\*Active patient registrations on the NHR. Patients may be registered at more than one centre.

	Sep-2021	Oct-2021	Nov-2021	Dec-2021	Jan-2022	Feb-2022	Mar-2022	Apr-2022	May-2022	Jun-2022	Jul-2022	Aug-2022
Active patients registered												
ADA 2	0	0	1	0	0	0	0	0	0	0	0	0
Congenital dyseythropoietic anaemia type 1	0	0	0	0	1	0	1	0	1	1	0	0
Congenital dyseythropoietic anaemia type II	1	0	0	0	0	0	0	0	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	1	0	0	0	0	0	0	0	0	1	0
Congenital dyseythropoietic anaemia type VI	0	0	0	0	0	0	0	0	0	0	0	0
Diamond Blackfan Anaemia	2	2	1	0	1	4	4	1	1	4	3	3
Glucose Phosphate Isomerase Deficiency	0	0	0	0	1	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	0	0	0	0	0	0	0	1	0	0	0	0
Methaemoglobin	0	0	0	0	1	1	0	0	0	1	1	1
Other rare anaemia cause unknown	8	6	11	4	5	8	14	8	7	11	7	14
Pyruvate Kinase Deficiency	0	1	2	2	0	1	4	1	1	2	0	1
Sideroblastic anaemia	1	0	1	0	1	0	1	0	1	2	0	0
Transfusion dependent membrane disorders	0	1	0	0	0	1	1	0	0	0	0	0

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Unstable haemoglobin	0	0	0	0	0	0	0	0	1	4	0	0	0
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## New and cumulative patient registrations diagnosed with another rare inherited anaemia (other) by month and secondary diagnosis.

	Sep-2021	Oct-2021	Nov-2021	Dec-2021	Jan-2022	Feb-2022	Mar-2022	Apr-2022	May-2022	Jun-2022	Jul-2022	Aug-2022
Cumulative patients registered												
ADA 2	0	0	1	1	1	1	1	1	1	1	1	1
Congenital dyseythropoietic anaemia type I	6	6	6	6	7	7	8	8	9	10	10	10
Congenital dyseythropoietic anaemia type II	7	7	7	7	7	7	7	7	7	7	7	7
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	9	10	10	10	10	10	10	10	10	10	11	11
Congenital dyseythropoietic anaemia type VI	0	0	0	0	0	0	0	0	0	0	0	0
Diamond Blackfan Anaemia	81	83	84	84	85	89	93	94	95	99	102	105
Glucose Phosphate Isomerase Deficiency	0	0	0	0	1	1	1	1	1	1	1	1
Hexokinase Deficiency	0	0	0	0	0	0	0	0	0	0	0	0
High affinity haemoglobin haemoglobin	2	2	2	2	2	2	2	3	3	3	3	3
Methaemoglobin	1	1	1	1	2	3	3	3	3	4	5	6
Other rare anaemia cause unknown	372	378	389	393	398	406	420	428	435	446	453	467
Pyruvate Kinase Deficiency	53	54	56	58	58	59	63	64	65	67	67	68

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Sideroblastic anaemia	25	25	26	26	27	27	28	28	29	31	31	31
Transfusion dependent membrane disorders	0	1	1	1	1	2	3	3	3	3	3	3
Unstable haemoglobin	1	1	1	1	1	1	1	2	6	6	6	6