

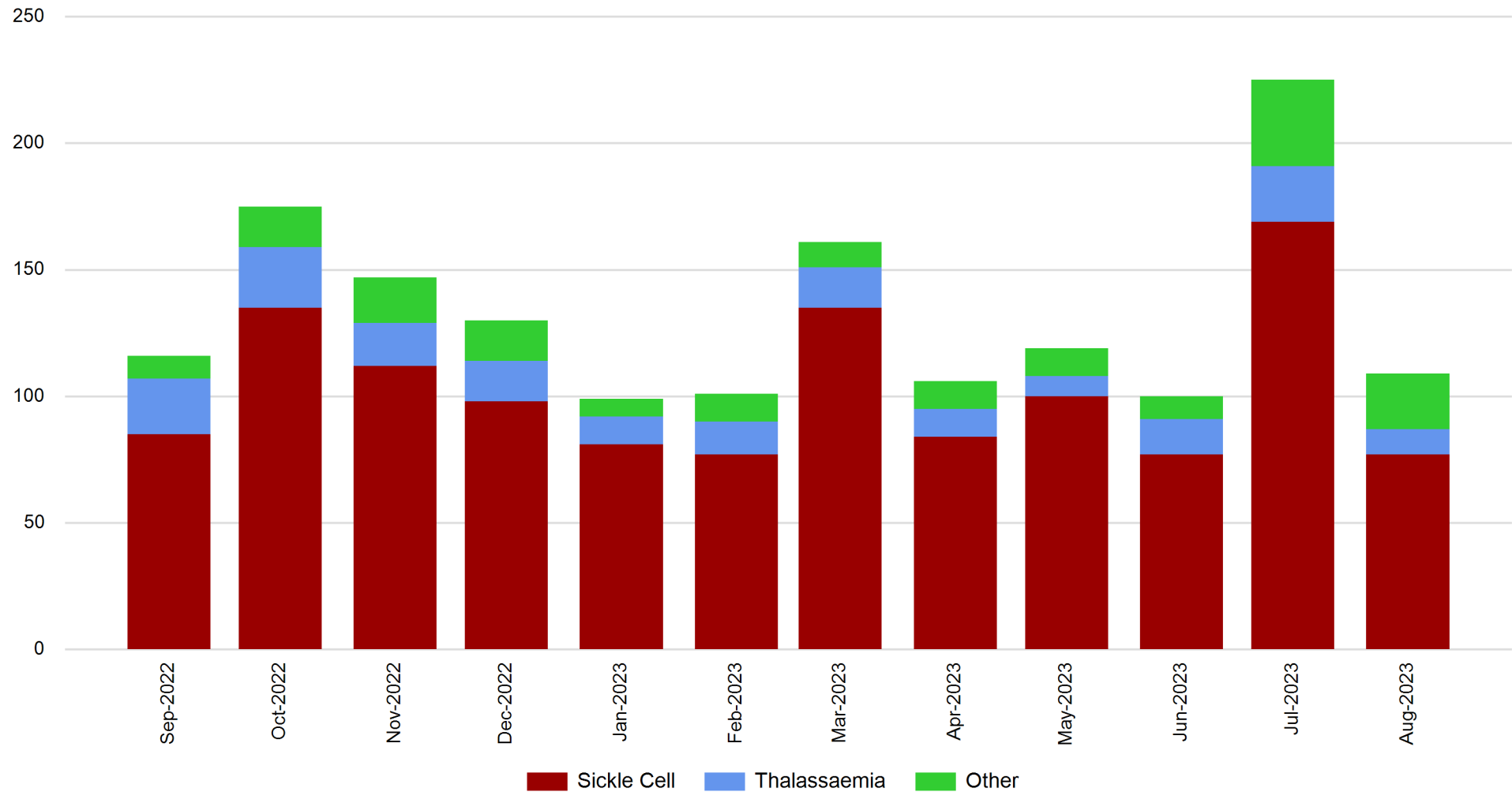
# NHR - Monthly status report - September 2023.



Showing data entered for active\* patients in the last 12 months up to 31/08/2023.

\*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 - September 2023.



Showing data entered for active\* patients in the last 12 months up to 31/08/2023.

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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-2022	85	22	9	14,821	2,179	706
Oct-2022	135	24	16	14,956	2,203	722
Nov-2022	112	17	18	15,068	2,220	740
Dec-2022	98	16	16	15,166	2,236	756
Jan-2023	81	11	7	15,247	2,247	763
Feb-2023	77	13	11	15,324	2,260	774
Mar-2023	135	16	10	15,459	2,276	784
Apr-2023	84	11	11	15,543	2,287	795
May-2023	100	8	11	15,643	2,295	806
Jun-2023	77	14	9	15,720	2,309	815
Jul-2023	169	22	34	15,889	2,331	849
Aug-2023	77	10	22	15,966	2,341	871

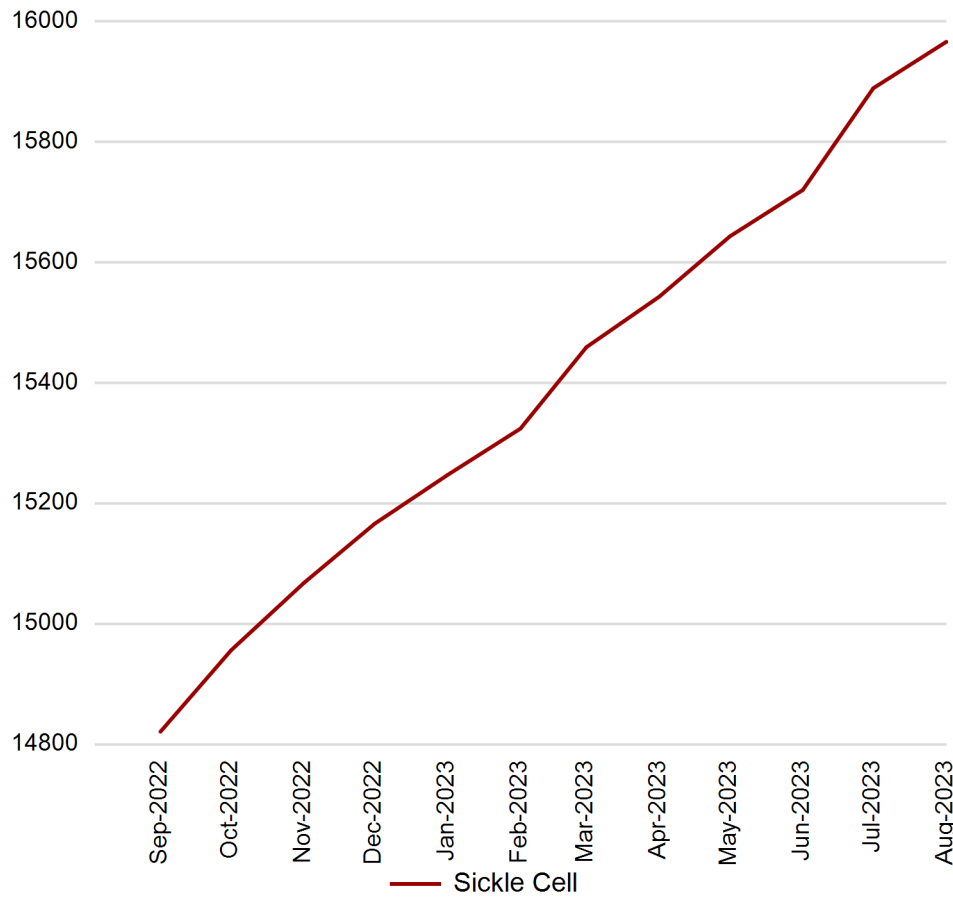
# NHR - Monthly status report - September 2023.



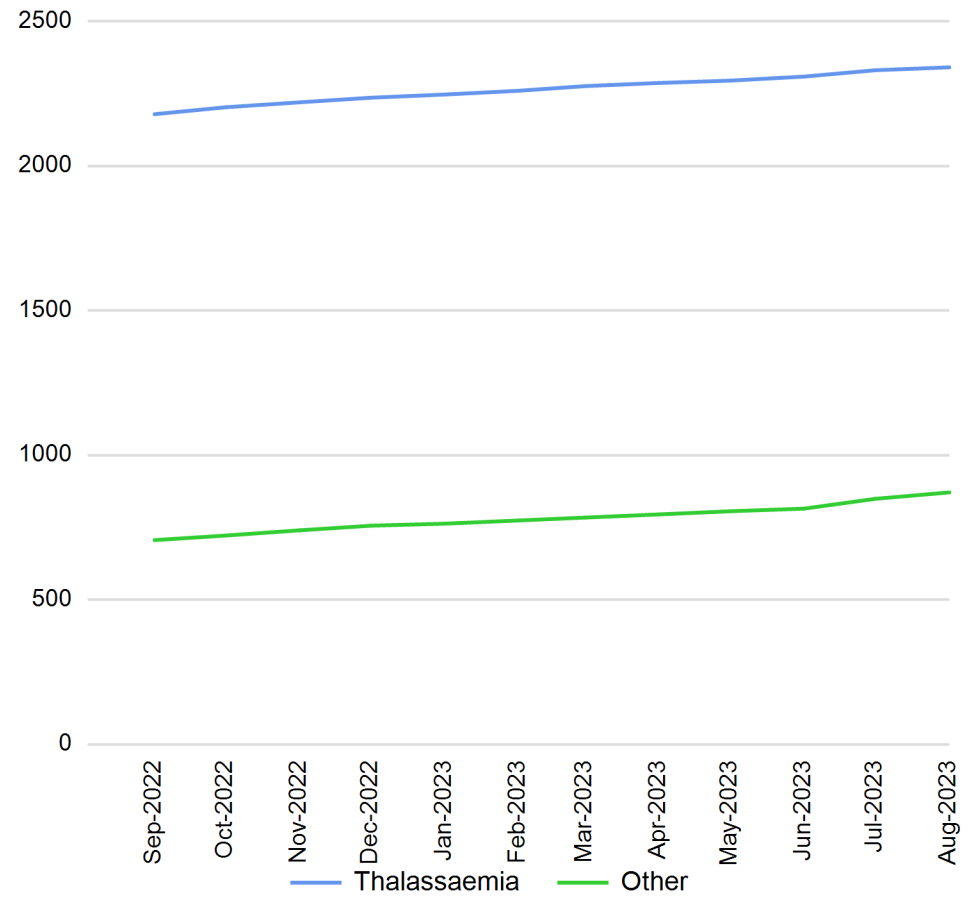
Showing data entered for active\* patients in the last 12 months up to 31/08/2023.

\*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-2022.



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



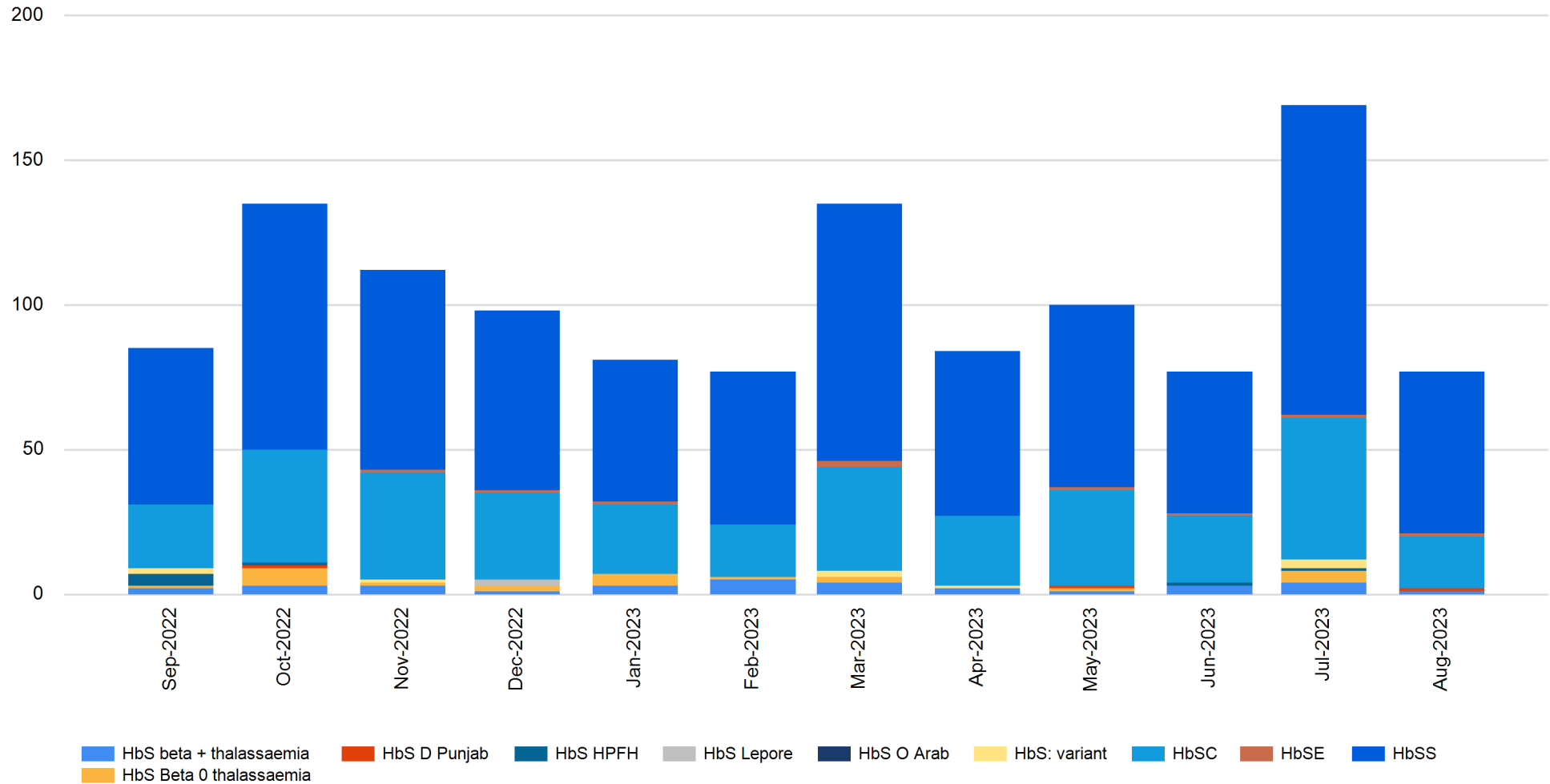
# NHR - Monthly status report - September 2023.



Showing data entered for active\* patients in the last 12 months up to 31/08/2023.

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



# NHR - Monthly status report - September 2023.



Showing data entered for active\* patients in the last 12 months up to 31/08/2023.

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

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

	Sep-2022	Oct-2022	Nov-2022	Dec-2022	Jan-2023	Feb-2023	Mar-2023	Apr-2023	May-2023	Jun-2023	Jul-2023	Aug-2023
<b>Active patients registered</b>												
Secondary diagnosis												
HbS beta + thalassaemia	2	3	3	1	3	5	4	2	1	3	4	1
HbS Beta 0 thalassaemia	1	6	1	2	4	1	2	0	1	0	4	0
HbS D Punjab	0	1	0	0	0	0	0	0	1	0	0	1
HbS HPFH	4	1	0	0	0	0	0	0	0	1	1	0
HbS Lepore	0	0	0	2	0	0	0	0	0	0	0	0
HbS O Arab	0	0	0	0	0	0	0	0	0	0	0	0
HbS: variant	2	0	1	0	0	0	2	1	0	0	3	0
HbSC	22	39	37	30	24	18	36	24	33	23	49	18
HbSE	0	0	1	1	1	0	2	0	1	1	1	1
HbSS	54	85	69	62	49	53	89	57	63	49	107	56
<b>Cumulative active patients</b>												
HbS beta + thalassaemia	609	612	615	616	619	624	628	630	631	634	638	639
HbS Beta 0 thalassaemia	276	282	283	285	289	290	292	292	293	293	297	297
HbS D Punjab	39	40	40	40	40	40	40	40	41	41	41	42
HbS HPFH	140	141	141	141	141	141	141	141	141	142	143	143
HbS Lepore	6	6	6	8	8	8	8	8	8	8	8	8
HbS O Arab	7	7	7	7	7	7	7	7	7	7	7	7
HbS: variant	21	21	22	22	22	22	24	25	25	25	28	28
HbSC	4,132	4,171	4,208	4,238	4,262	4,280	4,316	4,340	4,373	4,396	4,445	4,463
HbSE	33	33	34	35	36	36	38	38	39	40	41	42
HbSS	9,558	9,643	9,712	9,774	9,823	9,876	9,965	10,022	10,085	10,134	10,241	10,297

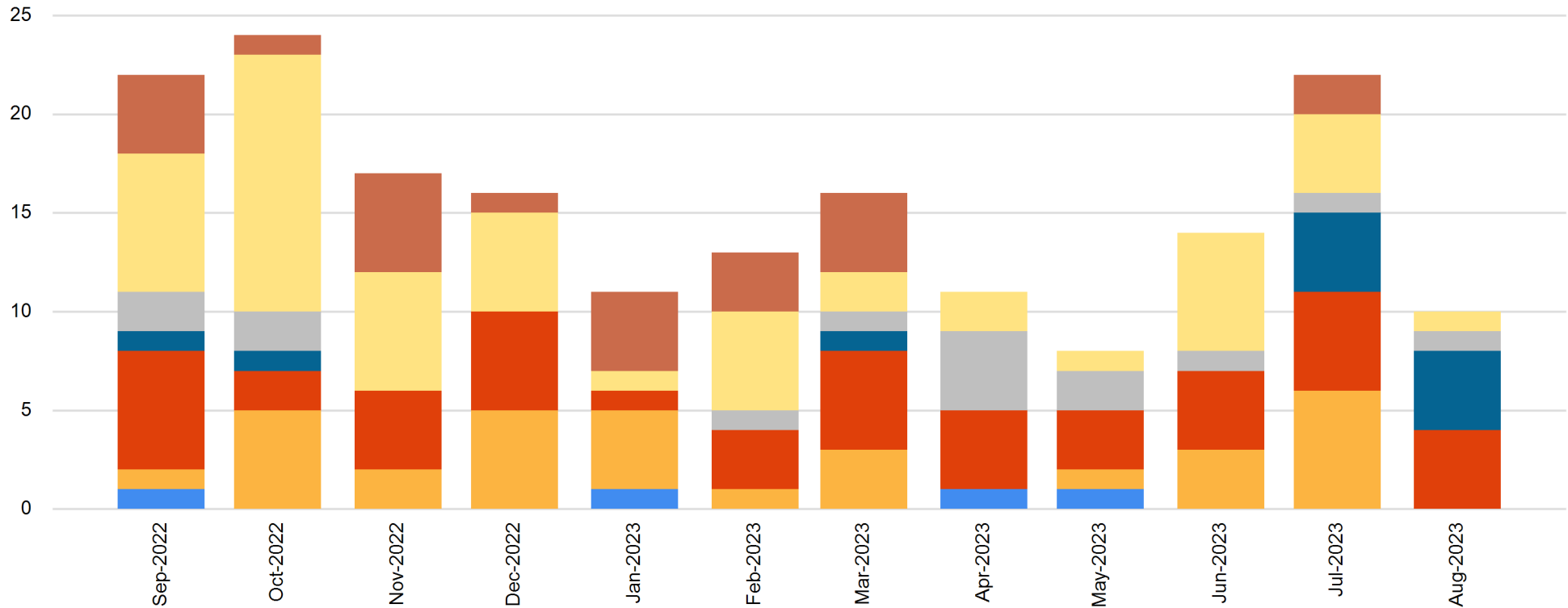
# NHR - Monthly status report - September 2023.



Showing data entered for active\* patients in the last 12 months up to 31/08/2023.

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

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



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



# NHR - Monthly status report - September 2023.



Showing data entered for active\* patients in the last 12 months up to 31/08/2023.

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

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

	Sep-2022	Oct-2022	Nov-2022	Dec-2022	Jan-2023	Feb-2023	Mar-2023	Apr-2023	May-2023	Jun-2023	Jul-2023	Aug-2023
<b>Active patients registered</b>												
Secondary diagnosis												
Alpha thalassaemia Major	1	0	0	0	1	0	0	1	1	0	0	0
Beta thalassaemia intermedia (excluding HbE thalassaemia)	1	5	2	5	4	1	3	0	1	3	6	0
Beta thalassaemia major (excluding HbE Beta thalassaemia)	6	2	4	5	1	3	5	4	3	4	5	4
E Beta thalassaemia (not transfusion dependant)	1	1	0	0	0	0	1	0	0	0	4	4
E beta thalassaemia (transfusion dependant)	2	2	0	0	0	1	1	4	2	1	1	1
HbH : variant	0	0	0	0	0	0	0	0	0	0	0	0
HbH Disease	7	13	6	5	1	5	2	2	1	6	4	1
HbH: constant spring	0	0	0	0	0	0	0	0	0	0	0	0
Other Thalassaemia	4	1	5	1	4	3	4	0	0	0	2	0
<b>Cumulative active patients</b>												
Alpha thalassaemia Major	3	3	3	3	4	4	4	5	6	6	6	6
Beta thalassaemia intermedia (excluding HbE thalassaemia)	347	352	354	359	363	364	367	367	368	371	377	377
Beta thalassaemia major (excluding HbE Beta thalassaemia)	1,151	1,153	1,157	1,162	1,163	1,166	1,171	1,175	1,178	1,182	1,187	1,191
E Beta thalassaemia (not transfusion dependant)	51	52	52	52	52	52	53	53	53	53	57	61
E beta thalassaemia (transfusion dependant)	70	72	72	72	72	73	74	78	80	81	82	83
HbH : variant	1	1	1	1	1	1	1	1	1	1	1	1
HbH Disease	393	406	412	417	418	423	425	427	428	434	438	439
HbH: constant spring	3	3	3	3	3	3	3	3	3	3	3	3
Other Thalassaemia	160	161	166	167	171	174	178	178	178	178	180	180



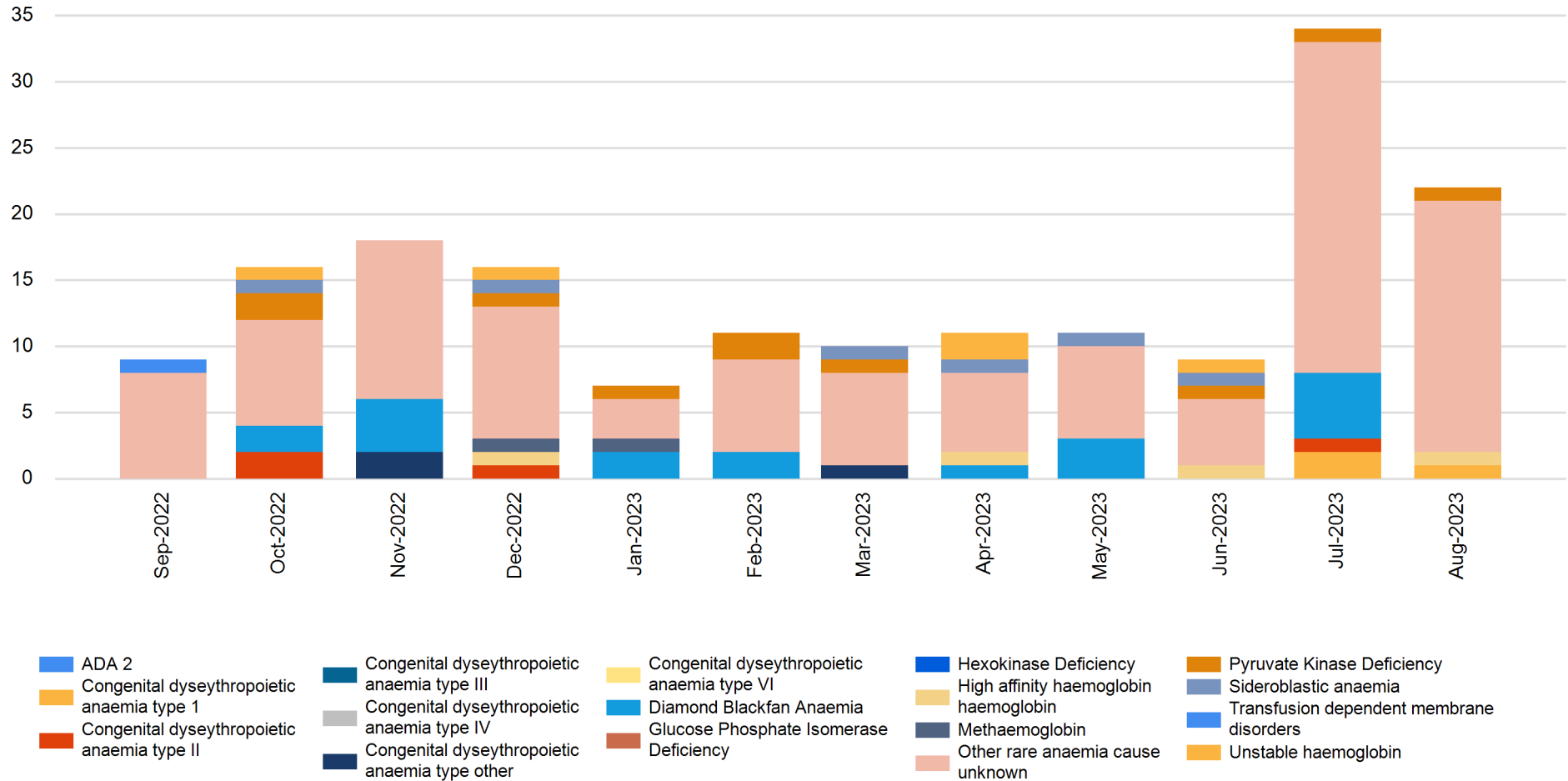
# NHR - Monthly status report - September 2023.



Showing data entered for active\* patients in the last 12 months up to 31/08/2023.

\*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.





# NHR - Monthly status report - September 2023.



Showing data entered for active\* patients in the last 12 months up to 31/08/2023.

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

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

	Sep-2022	Oct-2022	Nov-2022	Dec-2022	Jan-2023	Feb-2023	Mar-2023	Apr-2023	May-2023	Jun-2023	Jul-2023	Aug-2023
Active patients registered												
ADA 2	0	0	0	0	0	0	0	0	0	0	0	0
Congenital dyseythropoietic anaemia type 1	0	0	0	0	0	0	0	0	0	0	2	1
Congenital dyseythropoietic anaemia type II	0	2	0	1	0	0	0	0	0	0	1	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	0	2	0	0	0	1	0	0	0	0	0
Congenital dyseythropoietic anaemia type VI	0	0	0	0	0	0	0	0	0	0	0	0
Diamond Blackfan Anaemia	0	2	4	0	2	2	0	1	3	0	5	0
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	0	0	0	1	0	0	0	1	0	1	0	1
Methaemoglobin	0	0	0	1	1	0	0	0	0	0	0	0
Other rare anaemia cause unknown	8	8	12	10	3	7	7	6	7	5	25	19
Pyruvate Kinase Deficiency	0	2	0	1	1	2	1	0	0	1	1	1
Sideroblastic anaemia	0	1	0	1	0	0	1	1	1	1	0	0
Transfusion dependent membrane disorders	1	0	0	0	0	0	0	0	0	0	0	0
Unstable haemoglobin	0	1	0	1	0	0	0	2	0	1	0	0

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

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

	Sep-2022	Oct-2022	Nov-2022	Dec-2022	Jan-2023	Feb-2023	Mar-2023	Apr-2023	May-2023	Jun-2023	Jul-2023	Aug-2023
Cumulative patients registered												
ADA 2	1	1	1	1	1	1	1	1	1	1	1	1
Congenital dyseythropoietic anaemia type 1	10	10	10	10	10	10	10	10	10	10	12	13
Congenital dyseythropoietic anaemia type II	7	9	9	10	10	10	10	10	10	10	11	11
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	11	11	13	13	13	13	14	14	14	14	14	14
Congenital dyseythropoietic anaemia type VI	0	0	0	0	0	0	0	0	0	0	0	0
Diamond Blackfan Anaemia	107	109	113	113	115	117	117	118	121	121	126	126
Glucose Phosphate Isomerase Deficiency	1	1	1	1	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	4	4	4	5	5	5	5	6	6	7	7	8
Methaemoglobin	6	6	6	7	8	8	8	8	8	8	8	8
Other rare anaemia cause unknown	445	453	465	475	478	485	492	498	505	510	535	554
Pyruvate Kinase Deficiency	68	70	70	71	72	74	75	75	75	76	77	78
Sideroblastic anaemia	29	30	30	31	31	31	32	33	34	35	35	35
Transfusion dependent membrane disorders	4	4	4	4	4	4	4	4	4	4	4	4
Unstable haemoglobin	10	11	11	12	12	12	12	14	14	15	15	15