

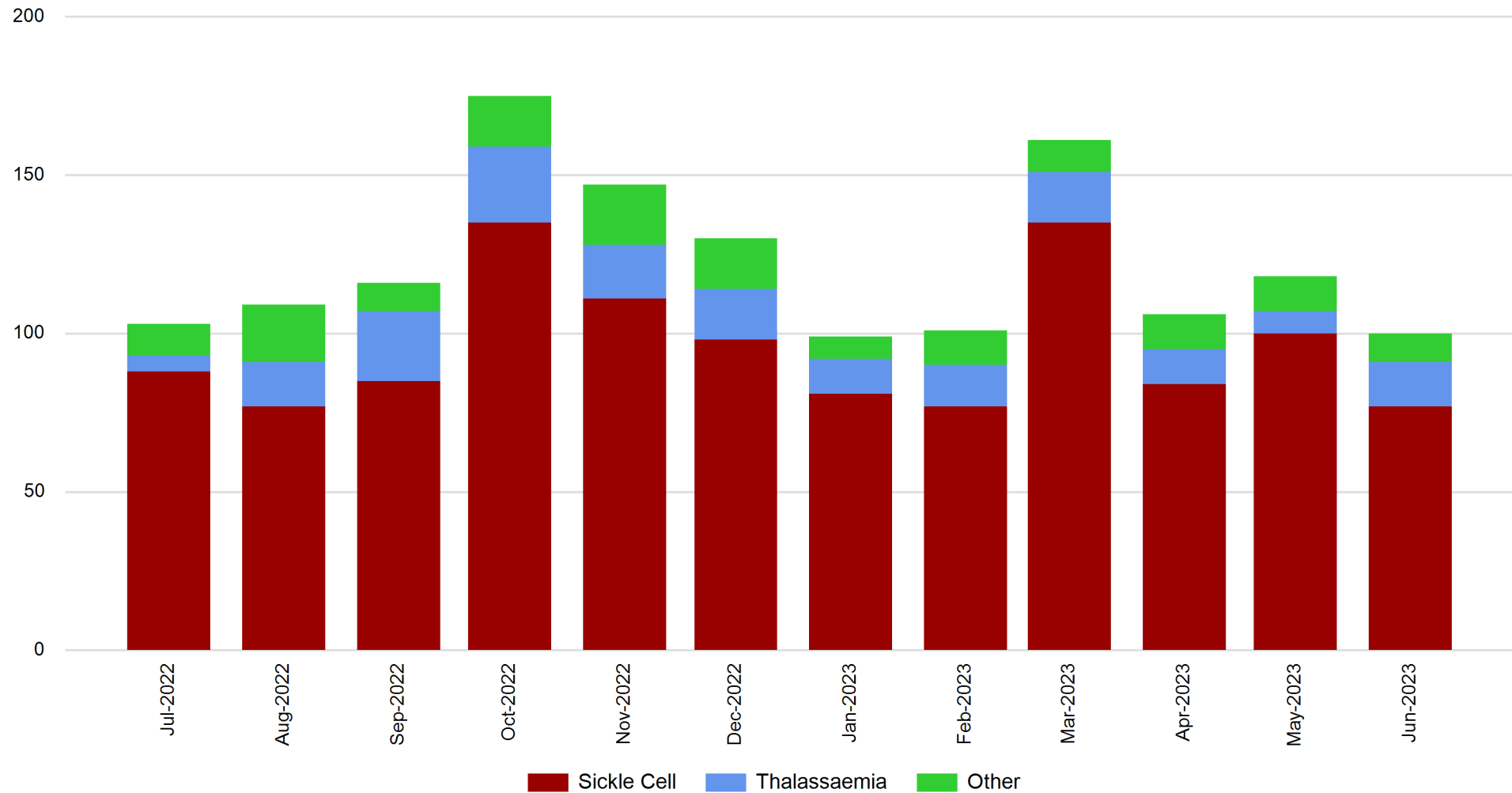
# NHR - Monthly status report - July 2023.



Showing data entered for active\* patients in the last 12 months up to 30/06/2023.

\*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 - July 2023.



Showing data entered for active\* patients in the last 12 months up to 30/06/2023.

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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
Jul-2022	88	5	10	14,668	2,152	679
Aug-2022	77	14	18	14,745	2,166	697
Sep-2022	85	22	9	14,830	2,188	706
Oct-2022	135	24	16	14,965	2,212	722
Nov-2022	111	17	19	15,076	2,229	741
Dec-2022	98	16	16	15,174	2,245	757
Jan-2023	81	11	7	15,255	2,256	764
Feb-2023	77	13	11	15,332	2,269	775
Mar-2023	135	16	10	15,467	2,285	785
Apr-2023	84	11	11	15,551	2,296	796
May-2023	100	7	11	15,651	2,303	807
Jun-2023	77	14	9	15,728	2,317	816

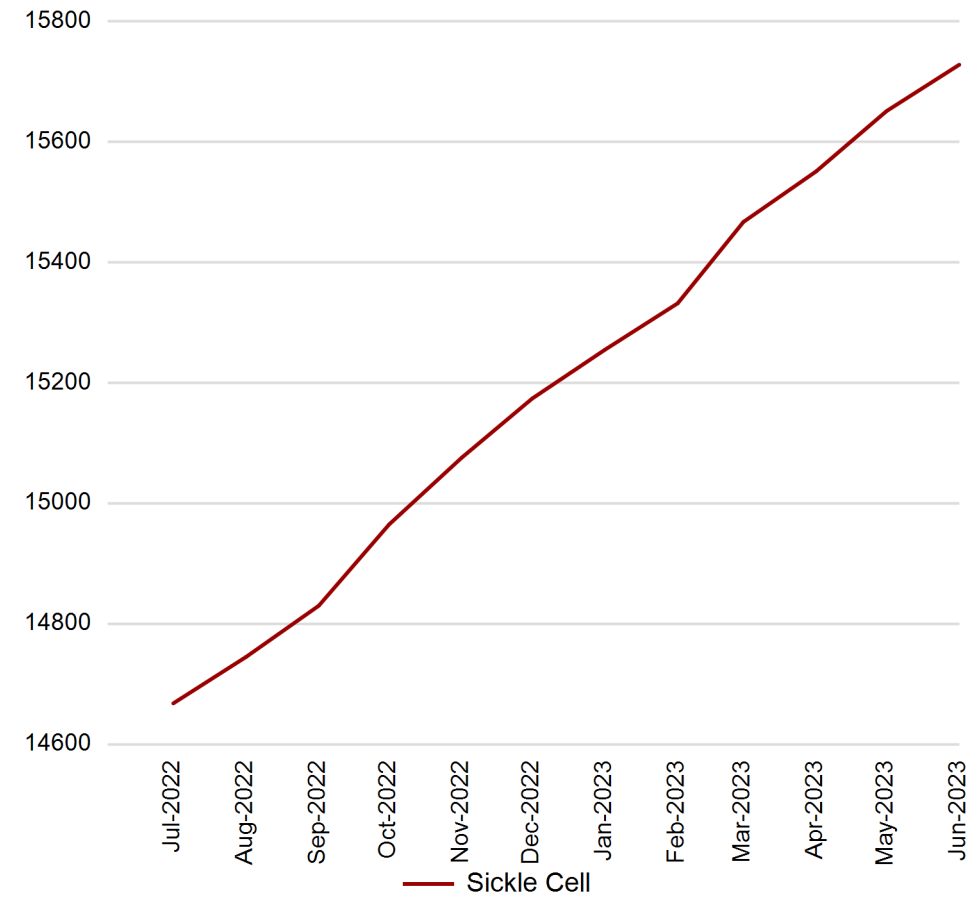
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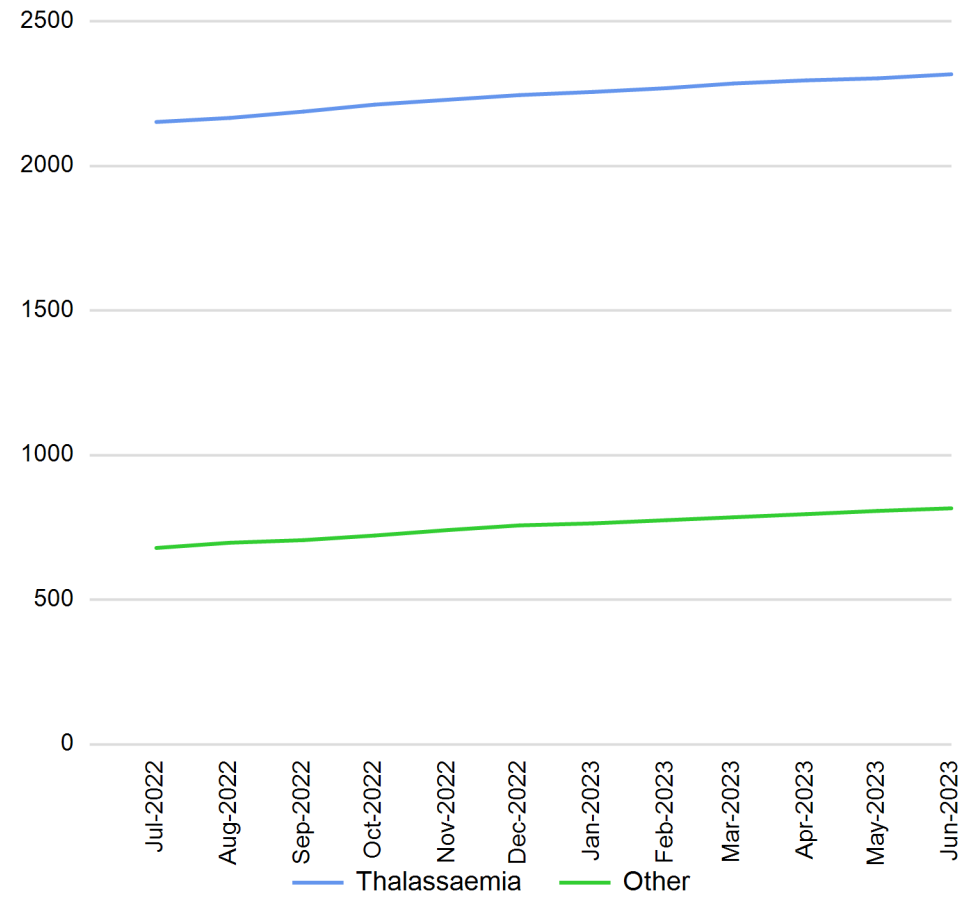
Showing data entered for active\* patients in the last 12 months up to 30/06/2023.

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



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



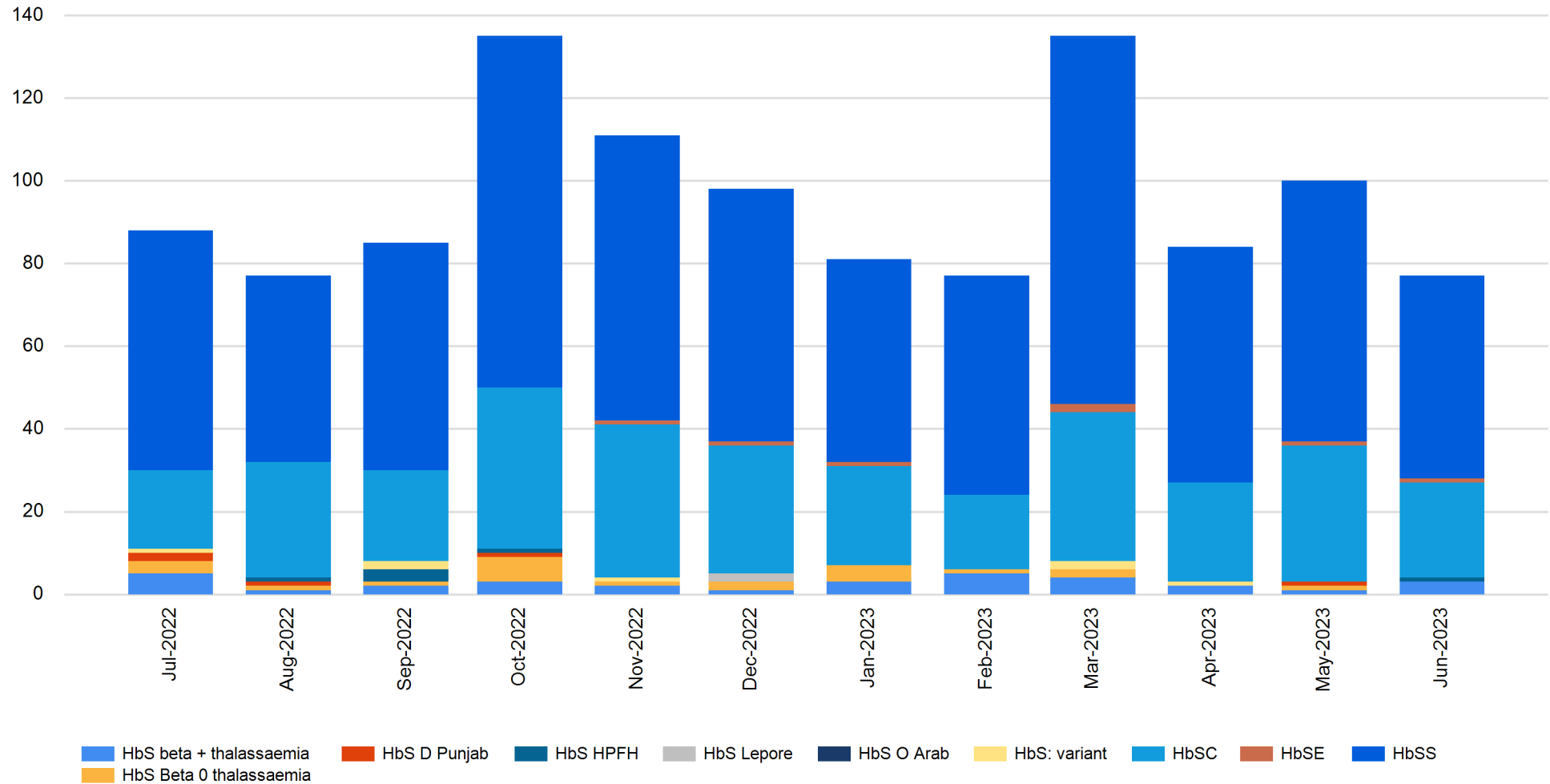
# NHR - Monthly status report - July 2023.



Showing data entered for active\* patients in the last 12 months up to 30/06/2023.

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



# NHR - Monthly status report - July 2023.



Showing data entered for active\* patients in the last 12 months up to 30/06/2023.

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

	Jul-2022	Aug-2022	Sep-2022	Oct-2022	Nov-2022	Dec-2022	Jan-2023	Feb-2023	Mar-2023	Apr-2023	May-2023	Jun-2023
<b>Active patients registered</b>												
Secondary diagnosis												
HbS beta + thalassaemia	5	1	2	3	2	1	3	5	4	2	1	3
HbS Beta 0 thalassaemia	3	1	1	6	1	2	4	1	2	0	1	0
HbS D Punjab	2	1	0	1	0	0	0	0	0	0	1	0
HbS HPFH	0	1	3	1	0	0	0	0	0	0	0	1
HbS Lepore	0	0	0	0	0	2	0	0	0	0	0	0
HbS O Arab	0	0	0	0	0	0	0	0	0	0	0	0
HbS: variant	1	0	2	0	1	0	0	0	2	1	0	0
HbSC	19	28	22	39	37	31	24	18	36	24	33	23
HbSE	0	0	0	0	1	1	1	0	2	0	1	1
HbSS	58	45	55	85	69	61	49	53	89	57	63	49
<b>Cumulative active patients</b>												
HbS beta + thalassaemia	605	606	608	611	613	614	617	622	626	628	629	632
HbS Beta 0 thalassaemia	274	275	276	282	283	285	289	290	292	292	293	293
HbS D Punjab	38	39	39	40	40	40	40	40	40	40	41	41
HbS HPFH	135	136	139	140	140	140	140	140	140	140	140	141
HbS Lepore	6	6	6	6	6	8	8	8	8	8	8	8
HbS O Arab	7	7	7	7	7	7	7	7	7	7	7	7
HbS: variant	19	19	21	21	22	22	22	22	24	25	25	25
HbSC	4,085	4,113	4,135	4,174	4,211	4,242	4,266	4,284	4,320	4,344	4,377	4,400
HbSE	33	33	33	33	34	35	36	36	38	38	39	40
HbSS	9,466	9,511	9,566	9,651	9,720	9,781	9,830	9,883	9,972	10,029	10,092	10,141

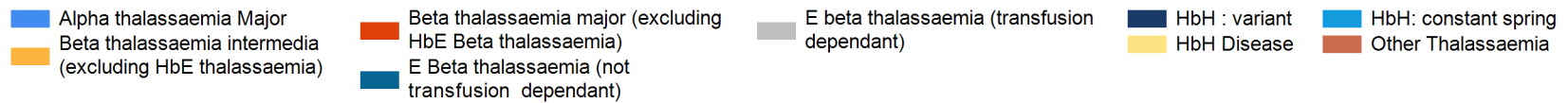
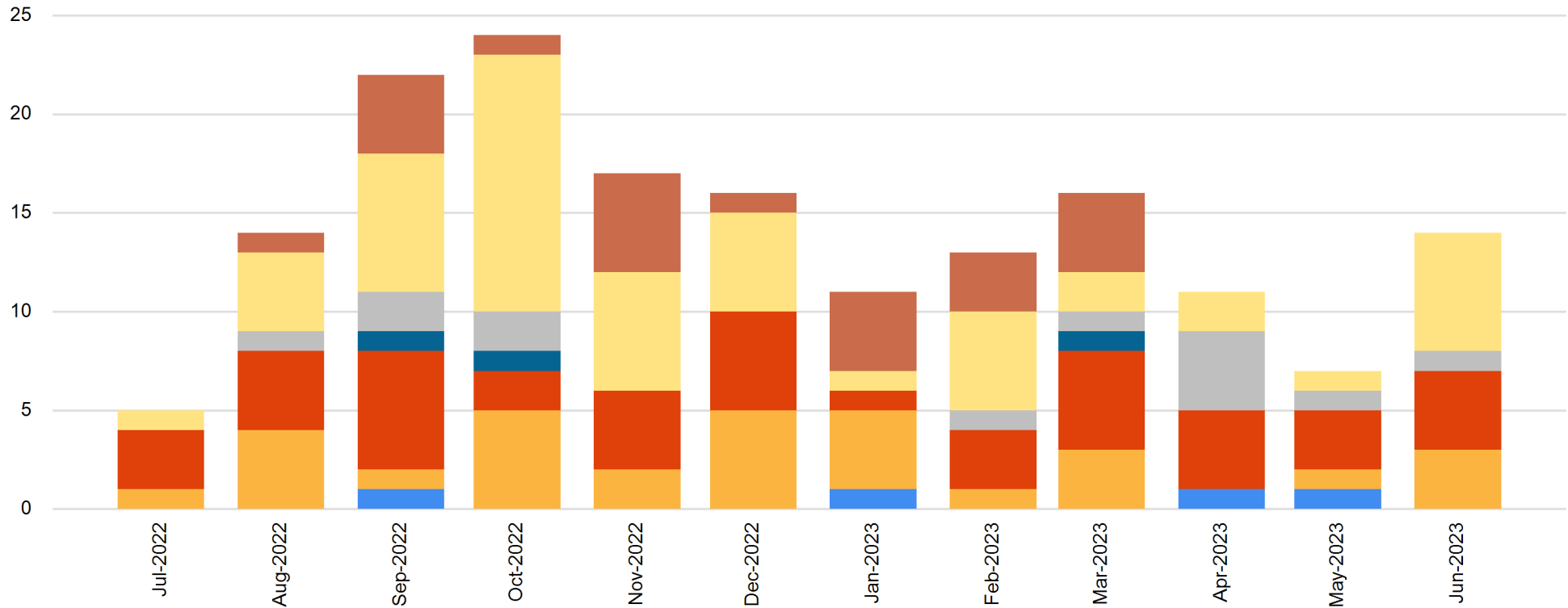
# NHR - Monthly status report - July 2023.



Showing data entered for active\* patients in the last 12 months up to 30/06/2023.

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

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



# NHR - Monthly status report - July 2023.



Showing data entered for active\* patients in the last 12 months up to 30/06/2023.

\*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.

	Jul-2022	Aug-2022	Sep-2022	Oct-2022	Nov-2022	Dec-2022	Jan-2023	Feb-2023	Mar-2023	Apr-2023	May-2023	Jun-2023
<b>Active patients registered</b>												
Secondary diagnosis												
Alpha thalassaemia Major	0	0	1	0	0	0	1	0	0	1	1	0
Beta thalassaemia intermedia (excluding HbE thalassaemia)	1	4	1	5	2	5	4	1	3	0	1	3
Beta thalassaemia major (excluding HbE Beta thalassaemia)	3	4	6	2	4	5	1	3	5	4	3	4
E Beta thalassaemia (not transfusion dependant)	0	0	1	1	0	0	0	0	1	0	0	0
E beta thalassaemia (transfusion dependant)	0	1	2	2	0	0	0	1	1	4	1	1
HbH : variant	0	0	0	0	0	0	0	0	0	0	0	0
HbH Disease	1	4	7	13	6	5	1	5	2	2	1	6
HbH: constant spring	0	0	0	0	0	0	0	0	0	0	0	0
Other Thalassaemia	0	1	4	1	5	1	4	3	4	0	0	0
<b>Cumulative active patients</b>												
Alpha thalassaemia Major	2	2	3	3	3	3	4	4	4	5	6	6
Beta thalassaemia intermedia (excluding HbE thalassaemia)	342	346	347	352	354	359	363	364	367	367	368	371
Beta thalassaemia major (excluding HbE Beta thalassaemia)	1,145	1,149	1,155	1,157	1,161	1,166	1,167	1,170	1,175	1,179	1,182	1,186
E Beta thalassaemia (not transfusion dependant)	50	50	51	52	52	52	52	52	53	53	53	53
E beta thalassaemia (transfusion dependant)	67	68	70	72	72	72	72	73	74	78	79	80
HbH : variant	1	1	1	1	1	1	1	1	1	1	1	1
HbH Disease	385	389	396	409	415	420	421	426	428	430	431	437
HbH: constant spring	3	3	3	3	3	3	3	3	3	3	3	3
Other Thalassaemia	157	158	162	163	168	169	173	176	180	180	180	180



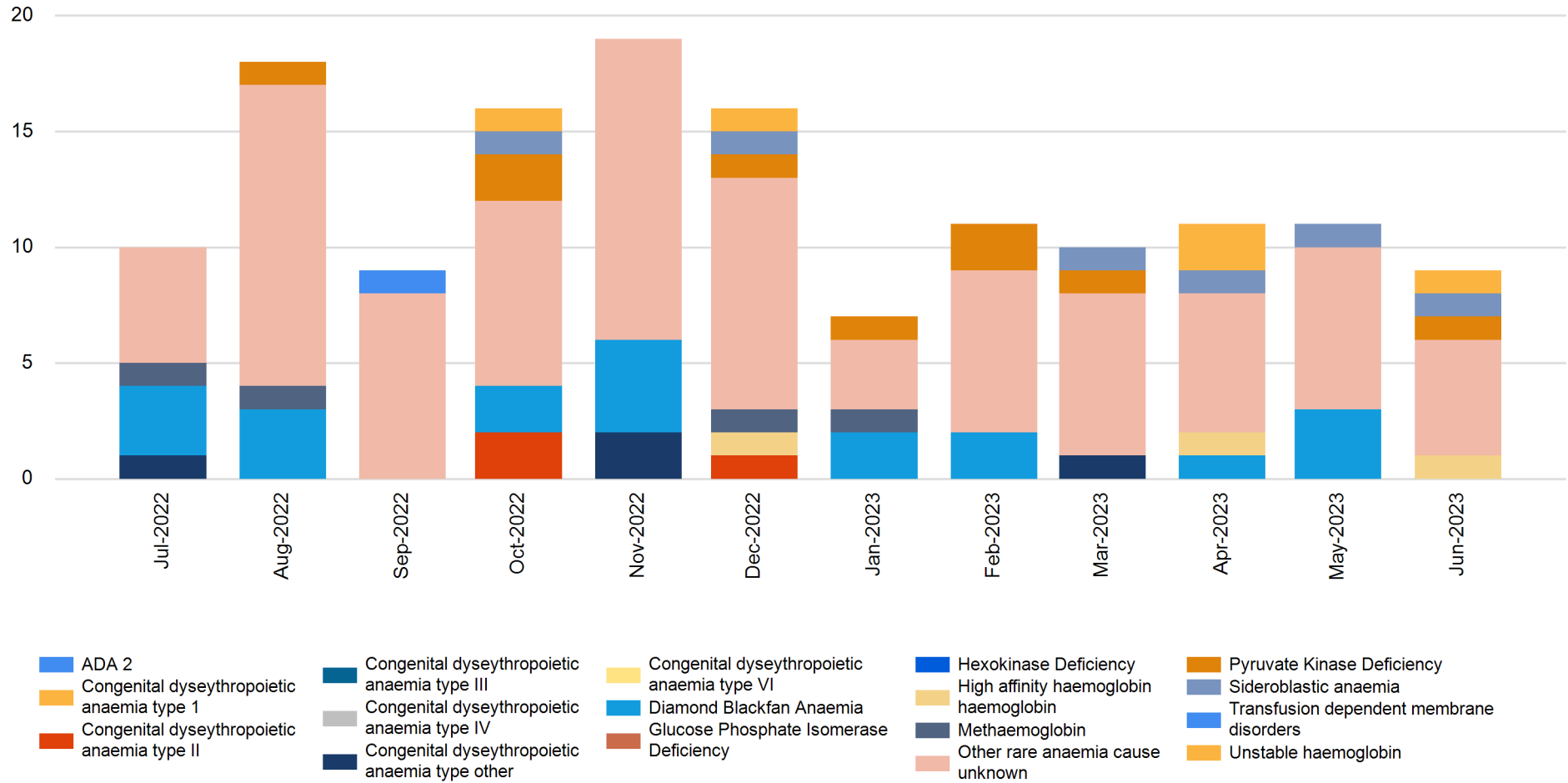
# NHR - Monthly status report - July 2023.



Showing data entered for active\* patients in the last 12 months up to 30/06/2023.

\*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 - July 2023.



Showing data entered for active\* patients in the last 12 months up to 30/06/2023.

\*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.

	Jul-2022	Aug-2022	Sep-2022	Oct-2022	Nov-2022	Dec-2022	Jan-2023	Feb-2023	Mar-2023	Apr-2023	May-2023	Jun-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	0	0
Congenital dyseythropoietic anaemia type II	0	0	0	2	0	1	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	1	0	0	0	2	0	0	0	1	0	0	0
Congenital dyseythropoietic anaemia type VI	0	0	0	0	0	0	0	0	0	0	0	0
Diamond Blackfan Anaemia	3	3	0	2	4	0	2	2	0	1	3	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	0	0	1	0	0	0	1	0	1
Methaemoglobin	1	1	0	0	0	1	1	0	0	0	0	0
Other rare anaemia cause unknown	5	13	8	8	13	10	3	7	7	6	7	5
Pyruvate Kinase Deficiency	0	1	0	2	0	1	1	2	1	0	0	1
Sideroblastic anaemia	0	0	0	1	0	1	0	0	1	1	1	1
Transfusion dependent membrane disorders	0	0	1	0	0	0	0	0	0	0	0	0
Unstable haemoglobin	0	0	0	1	0	1	0	0	0	2	0	1

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Showing data entered for active\* patients in the last 12 months up to 30/06/2023.

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

	Jul-2022	Aug-2022	Sep-2022	Oct-2022	Nov-2022	Dec-2022	Jan-2023	Feb-2023	Mar-2023	Apr-2023	May-2023	Jun-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	10	10
Congenital dyseythropoietic anaemia type II	7	7	7	9	9	10	10	10	10	10	10	10
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	11	11	13	13	13	13	14	14	14	14
Congenital dyseythropoietic anaemia type VI	0	0	0	0	0	0	0	0	0	0	0	0
Diamond Blackfan Anaemia	104	107	107	109	113	113	115	117	117	118	121	121
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	4	4	5	5	5	5	6	6	7
Methaemoglobin	5	6	6	6	6	7	8	8	8	8	8	8
Other rare anaemia cause unknown	424	437	445	453	466	476	479	486	493	499	506	511
Pyruvate Kinase Deficiency	67	68	68	70	70	71	72	74	75	75	75	76
Sideroblastic anaemia	29	29	29	30	30	31	31	31	32	33	34	35
Transfusion dependent membrane disorders	3	3	4	4	4	4	4	4	4	4	4	4
Unstable haemoglobin	10	10	10	11	11	12	12	12	12	14	14	15