SPAH

Scottish Paediatric and Adult Haemoglobinopathies Network

Annual Report 2025/26

The Network is supported by a dedicated programme team within Public Services Delivery Scotland (PSDS), consisting of:

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This document has been prepared by the National Services Directorate (NSD) of PSD Scotland on behalf of SPAH. Accountable to Scottish Government, PSD Scotland works at the heart of the health service providing national strategic services to the rest of NHS Scotland and other public sector organisations to help them deliver their services more efficiently and effectively. The SPAH Network is a collaboration of stakeholders involved in care of patients with haemoglobinopathies, who are supported by a PSD Scotland Programme Team to drive improvement across the care pathway.

Introduction

Background

The term ‘haemoglobinopathy’ covers a range of inherited blood conditions in which haemoglobin (the oxygen carrying protein in red blood cells) is either qualitatively or quantitatively abnormal. The two main disease groups are Sickle Cell Disease (SCD) and Thalassaemia. These are lifelong genetic disorders that often result in complex medical problems.

The Scottish Paediatric and Adult Haemoglobinopathies Network (SPAH) has a remit to ensure that equitable, high-quality care is delivered promptly to patients with haemoglobinopathies at all points in their journey, by a multidisciplinary healthcare team with knowledge of the condition. This includes minimising the risk of infections by immunisation and prophylaxis, management of drug therapies, transfusion needs and consequent iron overload to improve long-term health. Patient and parent education is also important to minimise the occurrence of sickle cell acute complications and managing these at home, where possible, thus reducing disruption to education and employment.

Due to the complex nature of Sickle Cell Disease and Thalassaemia, early involvement of the specialist haematology team is crucial to ensuring good patient outcomes. The network connects the various points of service delivery in the patient pathway and supports clinicians to work together effectively. Equity of care is supported through the use of standard guidelines and networking amongst the clinicians to share best practice.

Current position

Activity during 2025/26 reflected national prioritisation set during a period of review. Alongside evolving national planning arrangements, Managed Clinical Networks were asked to focus activity on a number of core priorities.

Looking ahead, and consistent with the direction set by the Health and Social Care Service Renewal Framework and Scotland's Population Health Framework (June 2025), and recognising that CEL 29 (2012) *Managed Clinical Networks: Supporting and Delivering the Healthcare Quality Strategy* remains the extant mandate for Managed Clinical Networks, SPAH will build on its established approach by undertaking a Strategic Needs Assessment to inform the 2026/27 workplan and ensure priorities remain aligned to population need, current pathways, available data and stakeholder perspectives.

The priorities for SPAH in 2025/26 were:

Priority Action	Progress
Emergency department engagement Raising awareness about sickle cell disease in Scotland and available resources.	Guidance signposted on SPAH website. Bulletin issued to emergency departments to highlight standards and available resources.
Transformative therapies Undertake further scoping work regarding developing services for patients in Scotland eligible for transformative therapy.	Advisory paper regarding Gene Therapy produced by SPAH and shared.
Transition Developing best practice guidance for transition from paediatric to adult services.	Scoping commenced. Guidance is under development

Out of the 19 business as usual objectives outlined in the 2025/26 workplan, 18 were successfully completed. The review of SPAH guidelines and documents in line with the document timetable continues, with some documents remaining incomplete due to limitations in clinical capacity. These guidelines were clinically risk assessed and deemed appropriate to remain on the SPAH website. This objective will be carried forward and prioritised in the 2026/27 workplan.

Highlights

Accident & Emergency Bulletin

The prevalence of sickle cell disease is increasing in Scotland, and this is reflected in A&E attendance. SPAH created a bulletin with the aim of highlighting the resources available to A&E teams when caring for these patients including Royal College of Emergency Medicine guidelines and SPAH guidance.

Information was also included relating to local haematology colleagues with an interest in sickle cell disease who would be able to support local teams.

Scottish Paediatric & Adult Haemoglobinopathies Network
A&E Information Bulletin - Spring 2026
Looking after patients with Sickle Cell Disease (SCD)

NHS SCOTLAND

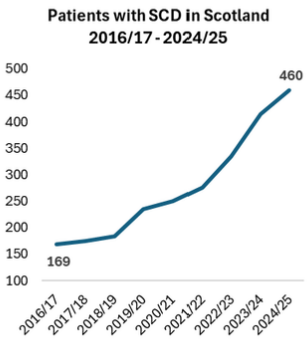
What is Sickle Cell Disease? (SCD)

SCD is a genetic disorder affecting red blood cells, causing them to become rigid and sickle-shaped. This leads to ischaemia causing:

- acute pain episodes (crises)
- organ damage (including chest crisis and stroke)
- infection risk due to hyposplenism.

Key reminders for A&E Teams

- Scottish patient numbers are increasing - currently 257 adults and 203 children.
- SCD complicates all medical events, even non-SCD presentations.
- Contact local haematology teams early.
- Urgent testing for SCD diagnosis can be done - discuss with haematology if needed.
- Use SPAH/RCEM resources for guidance and support.
- Mostly affects individuals from Black African, Caribbean and Middle Eastern backgrounds.



Acute Pain crisis presentations in Emergency Department

- **High priority triage** - Treat as medical emergency.
- **Pain relief:** Start opioids promptly and reassess regularly.
- **Consider oral/subcutaneous/nasal routes** especially if poor IV access.
- **Check for triggers:** infection, dehydration.
- **Monitor for complications:** chest crisis, strokes, fever, organ failure.
- Ensure not a non-sickle related diagnosis

Royal College of Emergency Medicine Best Practice Guidance

In 2024 the RCEM published **Best Practice Guidance for the management of acute presentations of SCD.** The full report is available on the RCEM Website.

Use QR code or click to link to RCEM report

Apply ACT NOW paradigm

A NALGESIA	**Give analgesia within 30 minutes** [NICE guidance] **Regular assessment of pain score** every 30 minutes until controlled and then every 4 hours. Refer to individualised care plan.
C OMPASSION	**Compassion**, kind, actively listen, provide reassure and keep informed **Consider IV fluids & antibiotics to treat infection and dehydration.**
T EST/TRIGGER	**Tests**: transfusion history/previous transfusion reactions. Blood tests (FBC, reticulocyte count, group and save, routine renal, liver & bone biochemistry, CRP), other tests as suggested by history e.g. CXR, MSU. **Trigger** – what precipitated the crisis? e.g. infection, dehydration, hypoxia, travel, pregnancy, stress, cold exposure.
N OTIFY	**Notify Specialist Haematology Team** **Notify** Next of Kin or advocate (when requested or in individual care plan)
O XYGEN	**Offer oxygen** supplementation if saturations <95% RA; regularly monitor oxygen saturations, including on room air, hourly for first 6 hours and then 4 hourly if stable as per NICE guidance
W ATCH	**Watch** and keep **warm** – regular observations of BP, pulse, respiratory rate, SpO2, temperature. Assess pain every 30 minutes until controlled. Escalate promptly (use local scoring e.g. NEWS2 for adults). Encourage fluids.

Ref: RCEM Best Practice Guideline 2024

Why this matters

Many patients report negative previous hospital experiences resulting in fear and anxiety when presenting to hospital.
'The **No One's Listening' (2021)** All Party Parliamentary Group Report highlighted:

- avoidable deaths & failures in care
- racial bias and stigma
- accusations of drug-seeking during pain crises.

NO ONE'S LISTENING:

Use QR code or click to link to No One's Listening Report

SPAH key resources

Guidance on the management of acute painful crisis is available on the SPAH website along with other Scottish guidelines for both paediatric and adult patients.

Manual red cell exchange (RCE) can be life saving for patients with SCD. It would be very unusual to perform this in an A&E but these education videos provide an overview of manual RCE as well as how it is performed.

Use QR codes or click to link to training videos

Case Discussion Meetings

SPAH continued to facilitate peer support for specialists through delivery of 5 case discussion meetings using Teams. There were 17 cases and 3 adverse events discussed across the year with an average attendance of 13 clinicians. This format supports patient care and allows sharing of clinical knowledge.

Website

The website had 6,486 visitors during 2025/26 and 26,466 views. This demonstrates the continued value of this resource, particularly when accessing clinical guidelines. The top 10 pages are in the table below:

Page	Visitors	Views
Home	6,486	26,466
News and Events	1,611	1,976
Patients and Families	1,505	1,962
Professional zone	1,412	1,650
Adult Protocols/Guidance	1,349	1,710
Reports	1,308	1,611
Paediatric Protocols/Guidance	1,072	1,326
About Us	1,038	1,146
Contact us	1,005	1,090
CAS/IT/Audit	867	1,041

Patients with haemoglobinopathies registered on the National Clinical Audit System

Patient demographics

The number of patients with haemoglobinopathies in Scotland continues to rise significantly, creating considerable pressure on services. Since 2014, patient numbers have increased by 209%. A reasonable assumption is continued growth of between 40-50 patients per year. It is clear that this is predominantly a genuine rise in numbers rather than more robust data collection. There are also now a number of Health Boards outside of the main centres that have small but rising numbers of patients. In recognition of these trends, SPAH has identified the need to review the model of care as part of the strategic needs assessment being progressed during 2026/27.

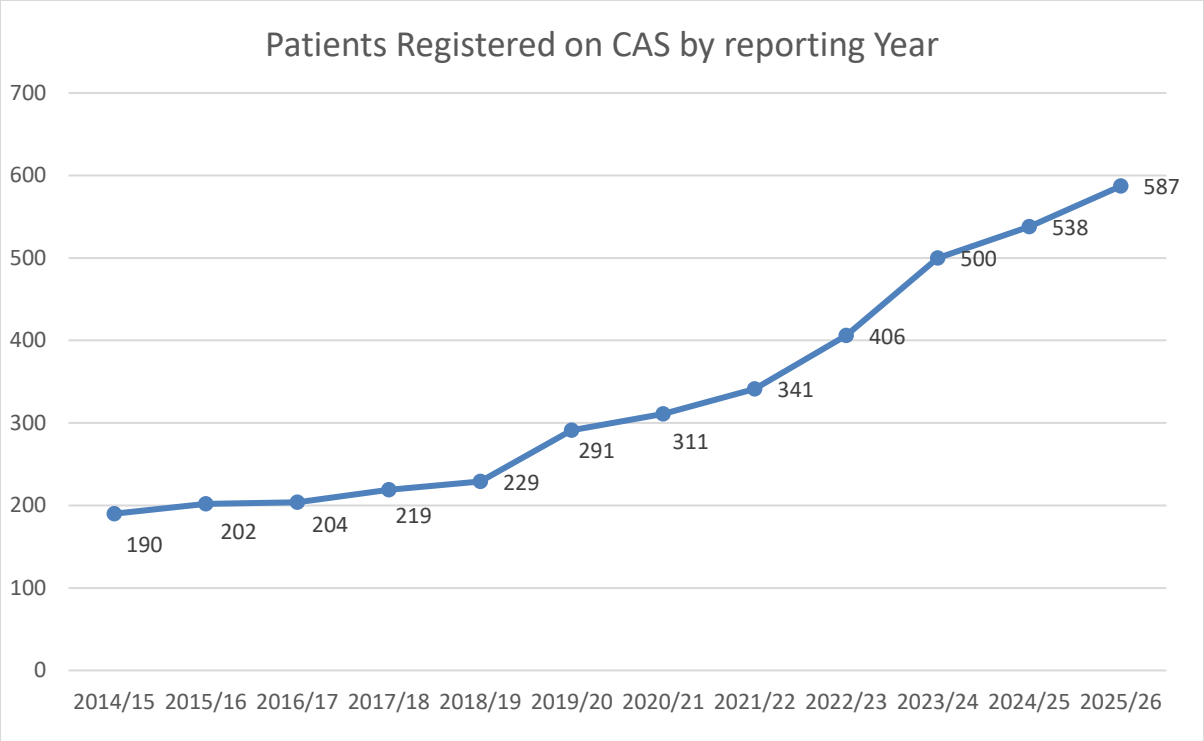


Figure 1: Patients recorded in the Clinical Audit System by Year

Total number of patients by Health Board

While patient numbers continue to increase within the larger Health Boards, the greatest proportional increases have been observed in smaller Health Boards. This reflects the increasingly widespread distribution of patients with haemoglobinopathies across Scotland and highlights the importance of ensuring access to specialist knowledge and support nationwide, as well as the important role of the Network in supporting this.

Total Patients by Health Board Within Last 5 years

Health Board of Residence	21/22	22/23	23/24	24/25	25/26	5 Year % Change
A&A	<5	6	8	15	18	350.00%
BORD					<5	0.00%
D&G	<5	<5	<5	<5	<5	0.00%
FIFE	<5	<5	7	8	12	1100.00%
FV	<5	7	13	15	15	275.00%
GG&C	177	189	213	230	252	42.37%
GRAM	56	81	85	88	86	53.57%
HIGH					<5	0.00%
LAN	20	24	31	35	42	110.00%
LOTH	55	65	104	111	124	125.45%
TAY	23	31	38	36	35	52.17%

Figure 2: Total patients by Health Board within last 5 years

Specific disease data by treatment centre

The largest group is patients with sickle cell disease, with the distribution across Scotland shown in the tables below:

Patients by Condition and Treatment Centre

Patient Treatment Centre	SICKLE CELL DISEASE	THALASSAEMIA INTERMEDIA	THALASSAEMIA MAJOR
A&A - ADULT	<5		<5
ABERDEEN - ADULTS	50	5	<5
ABERDEEN - CHILDREN	29		<5
DUMFRIES & GALLOWAY - ADULTS	<5		
DUNDEE - ADULTS	18	<5	<5
DUNDEE - CHILDREN	9	<5	<5
EDINBURGH - ADULTS	62	<5	6
EDINBURGH - CHILDREN	53	5	5
FORTH VALLEY	9		<5
GLASGOW - ADULTS	140	10	<5
GLASGOW - CHILDREN	121	13	16
HIGHLAND - ADULTS	<5		
LANARKSHIRE - ADULT	6		

Figure 3: Patients in Scotland by Condition and Treatment Centre

Adult & paediatric patient population by condition

Number of Active Patients by Condition

Condition	Total	Under 18	Over 18
SICKLE CELL DISEASE	503	217	286
THALASSAEMIA MAJOR	39	22	17
THALASSAEMIA INTERMEDIA	42	21	21

Figure 4: Total number of patients by condition

Adult & paediatric patient population per 100,000 population

The paediatric and adult patients registered on CAS by Health Board of Residence and by 100k of Head of Population is shown in the next two slides. This data is likely to have many uses, but in particular highlights the number of patients cared for by the tertiary paediatric centres who will be returning to the local Health Boards when they reach adulthood. Paediatric patients are cared for in one of 4 tertiary paediatric centres, but adult care is provided in Ayrshire & Arran, Dumfries & Galloway, Forth Valley, Greater Glasgow & Clyde, Grampian, Highland, Lanarkshire, Lothian and Tayside.

Number of Active Patients

Health Board of Residence	Total	Under 18	Over 18
A&A	18	13	5
BORD	<5	<5	<5
D&G	<5	<5	<5
FIFE	12	<5	8
FV	15	<5	11
GG&C	252	108	144
GRAM	86	32	54
HIGH	<5	<5	<5
LAN	42	30	12
LOTH	124	58	66
TAY	35	14	21

Figure 5: Total number of patients by Health Board

Active Patients per 100k Population

Health Board of Residence	Total	Under 18	Over 18
A&A	4.89 National Prevalence: 10.58	19.68 National Prevalence: 25.79	1.66 National Prevalence: 7.16
BORD	0.85	0.00	1.03
D&G	0.69	0.00	0.83
FIFE	3.20	5.75	2.62
FV	4.90	6.97	4.42
GG&C	20.70	48.73	14.46
GRAM	14.53	28.06	11.30
HIGH	0.31	0.00	0.37
LAN	6.19	22.74	2.20
LOTH	13.30	34.26	8.65
TAY	8.35	18.50	6.11

Figure 6: Total number of patients by Health Board per 100k population

Babies identified through newborn screening (NBS)

SPAH in conjunction with the Newborn Screening Laboratories collate data on the number of babies born with haemoglobinopathies.

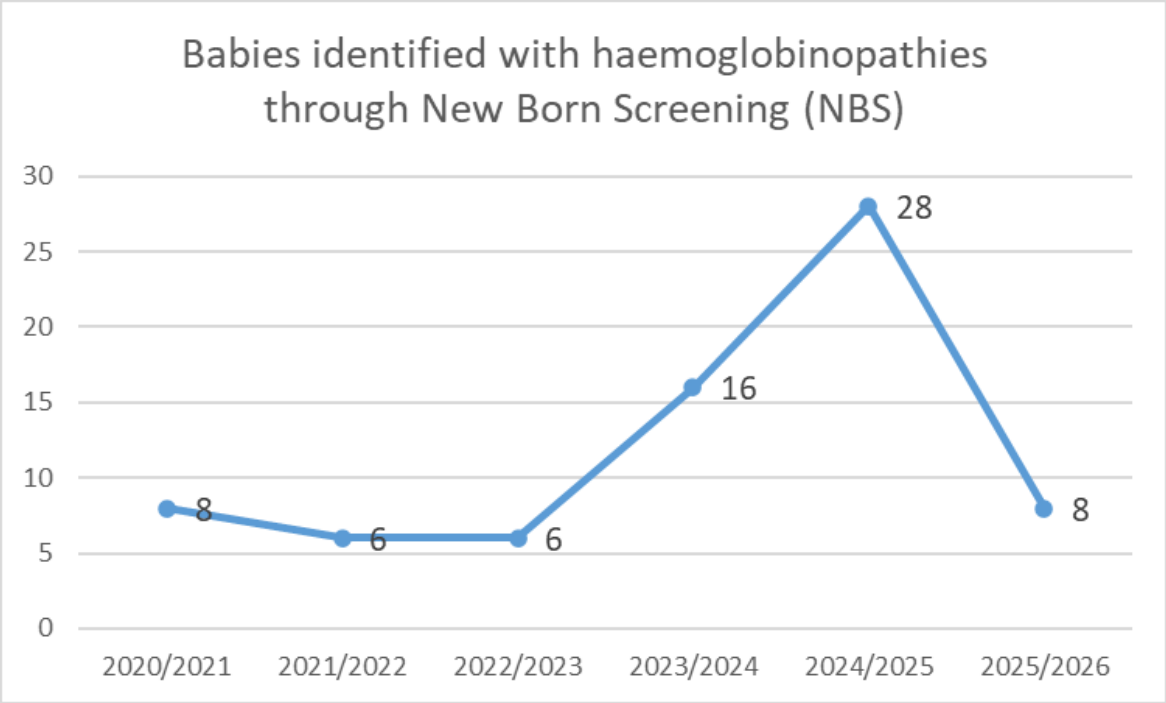


Figure 7: Babies identified through newborn screening over last 6 years

Reporting Against SPAH Key Performance Indicators

Measuring performance has once again been an objective for the network during 2025/26. Clinicians have continued to provide data to measure against 7 Key Performance Indicators (KPIs).

The KPI outputs are only as robust as the data entered into the system. Clinician time and challenges with accessing the CAS has had a significant impact on the data input into the CAS system, beyond the basic demographics. It is recognised that this is something that needs to be addressed going forward.

KPI data which is available within CAS is provided below.

KPI 1 – 100% of screen positive babies are seen by a paediatric haematologist or paediatrician within 8 weeks of referral from Newborn Screening.

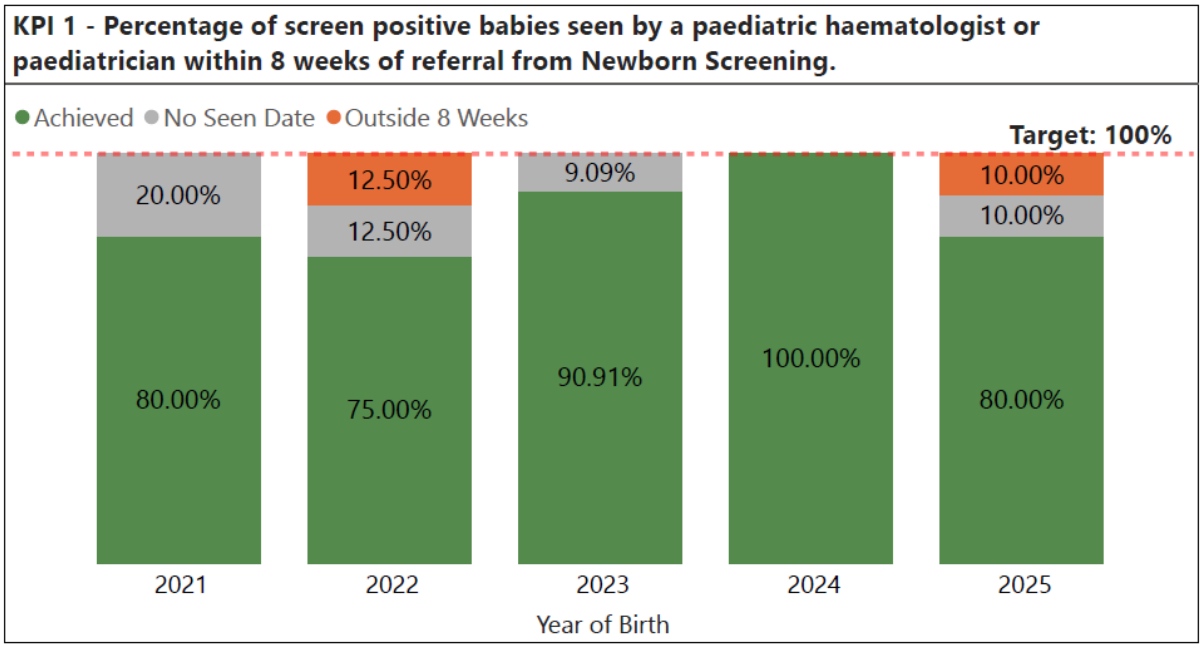


Figure 8: Percentage of screen positive babies seen by a paediatric haematologist or paediatrician within 8 weeks of referral from NBS. Results shown for last 5 years.

KPI 2 – 100% of screen positive babies in whom results of confirmatory testing are returned to the Newborn Screening Laboratory.

NB "No Form Data" relates to babies born outside NHS Scotland and therefore not reported through NBS.

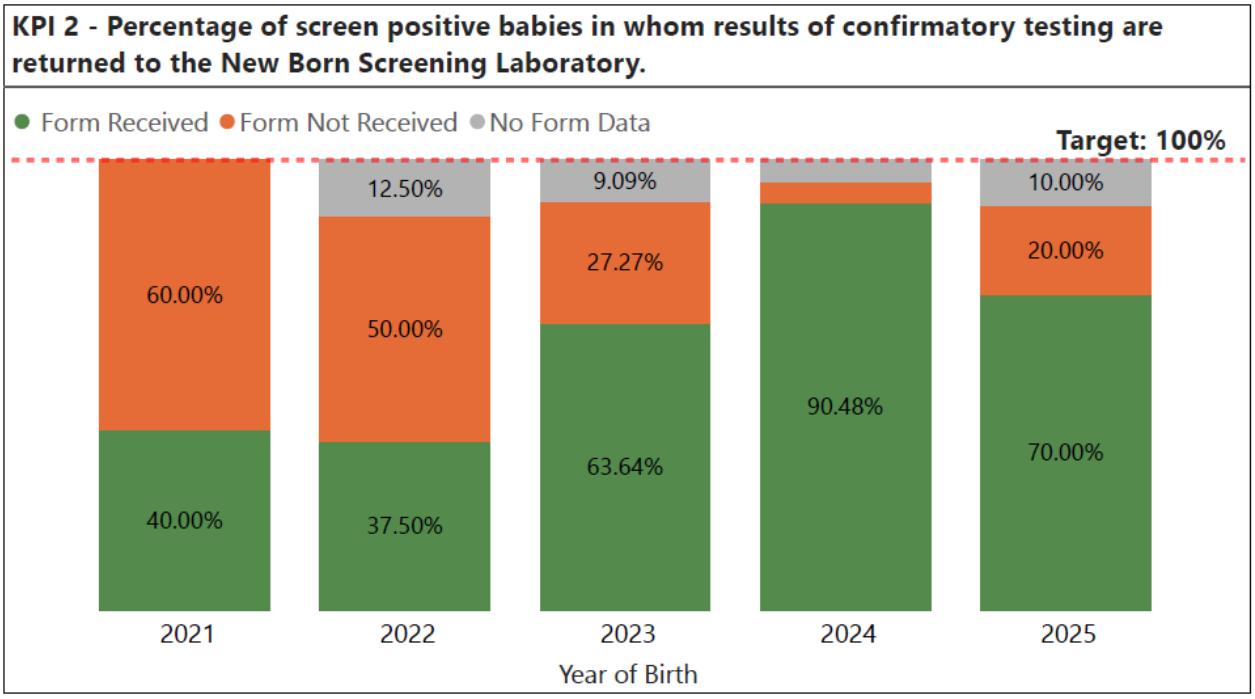


Figure 9: Percentage of screen positive babies in whom results of confirmatory testing are return to the NBS laboratory. Results shown for last 5 years.

KPI 3 - 100% of patients with sickle cell disease (SCD) are offered penicillin V (or alternative) by 3 months of age.

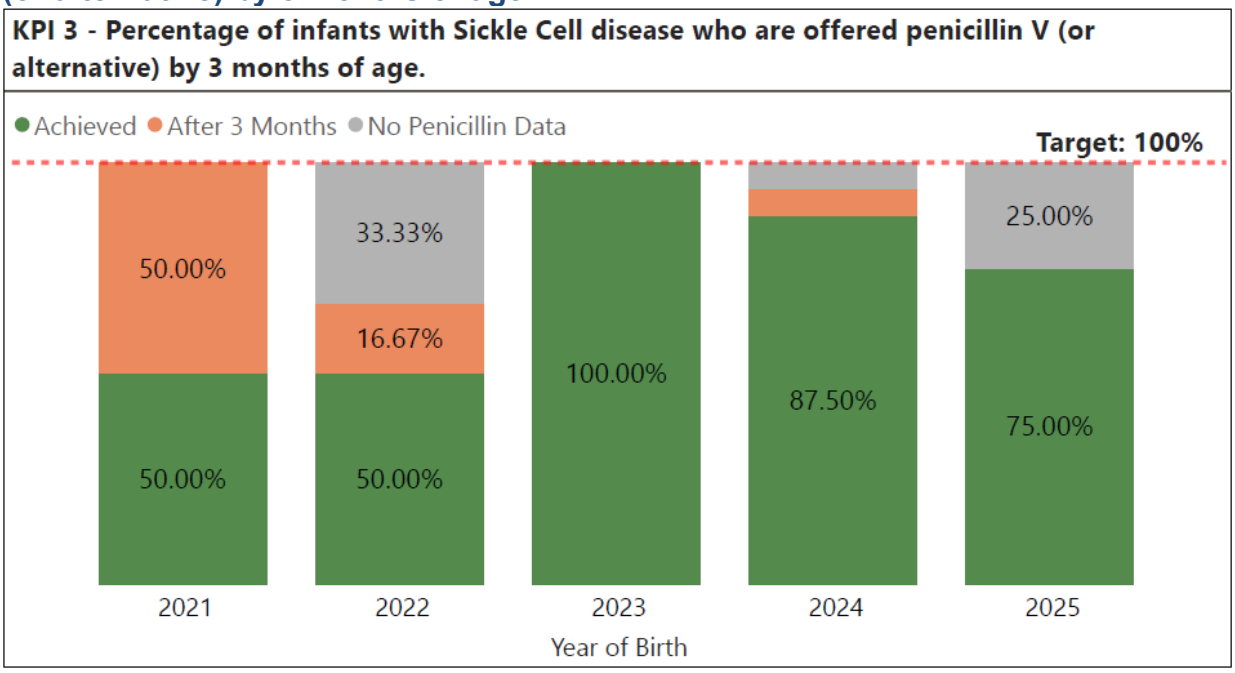


Figure 10: Percentage of infants with SCD who are offered penicillin V (or alternative) by 3 months of age. Results shown for last 5 years.

KPI 4 – 95% of patients should be given first Pneumovax (polycaccharide antigen) by 27 months and 5 yearly thereafter.

Access to data around vaccinations remains challenging. It should be noted that the clinicians do not believe that a significant number of patients are missing out on vaccines, but that the data is not being captured.

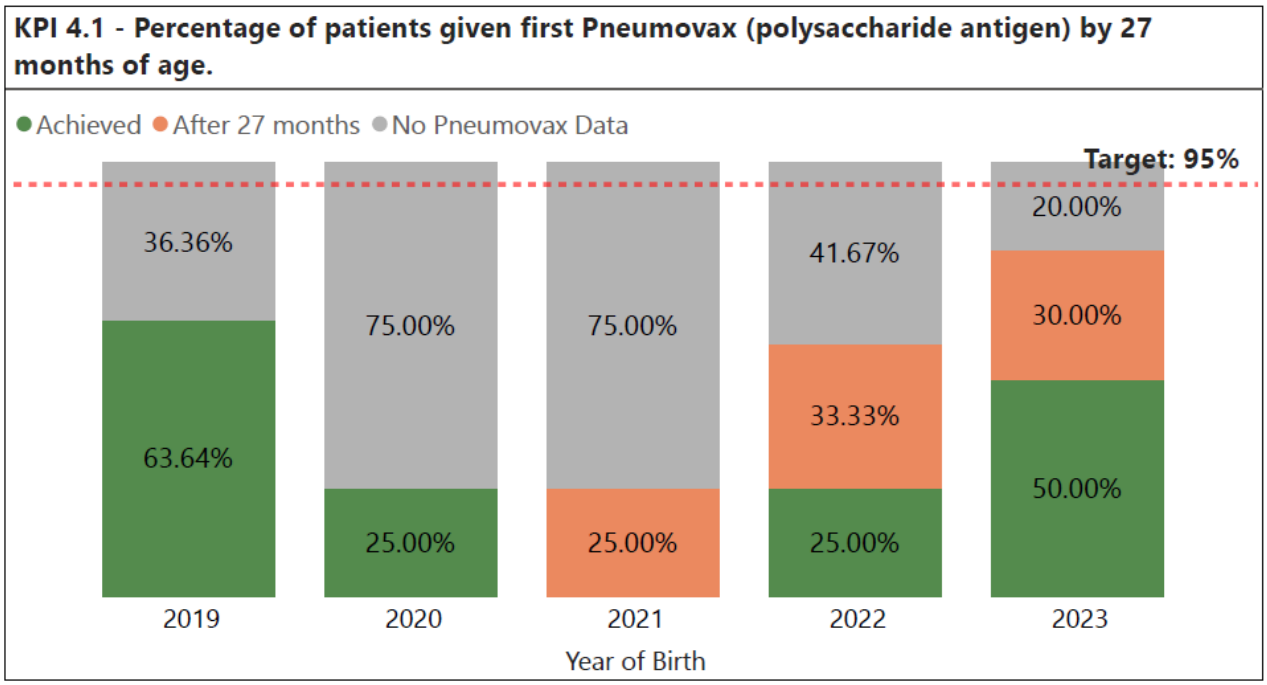


Figure 11: Percentage of patients given first Pneumovax by 27 months of age. Results shown for last 5 years.

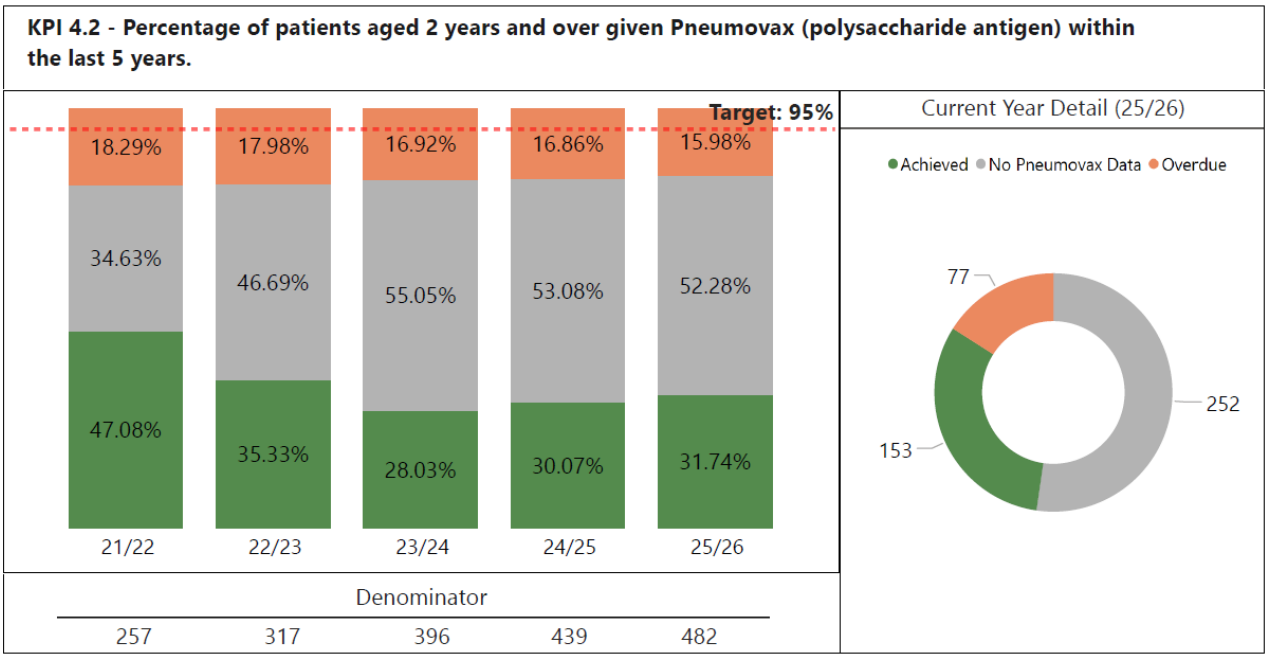


Figure 12: Percentage of patients aged 2 and over given Pneumovax within the last 5 years. Results shown for past 5 years.

KPI 5 – 100% of children with HbSS or HbS/Beta thalassemia aged 2-16 years offered an annual TCD scan.

The network is working with the clinical service and NSD to highlight the importance of this service.

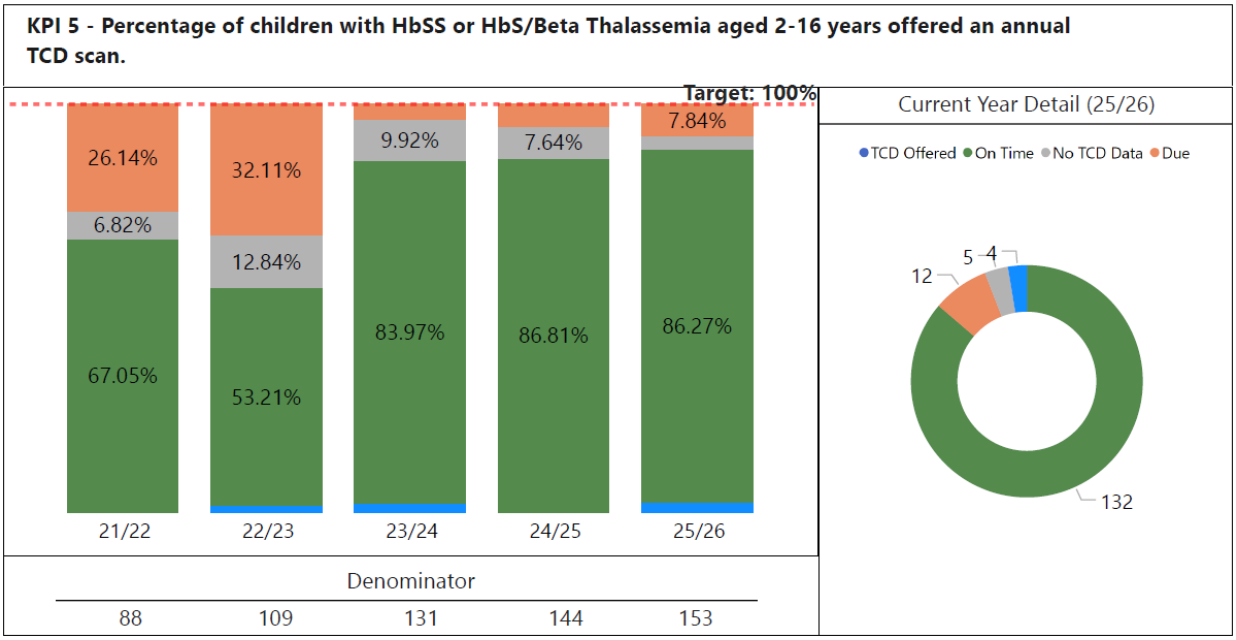


Figure 13: Percentage of children with HbSS or HbS/Beta thalassemia aged 2-16 offered an annual TCD scan. Results shown for past 5 years.

KPI 6 – 90% of thalassemia patients on regular transfusion undergoing appropriate monitoring of iron overload (annual MRI) as per guidelines. MRI scan within the last 12 months.

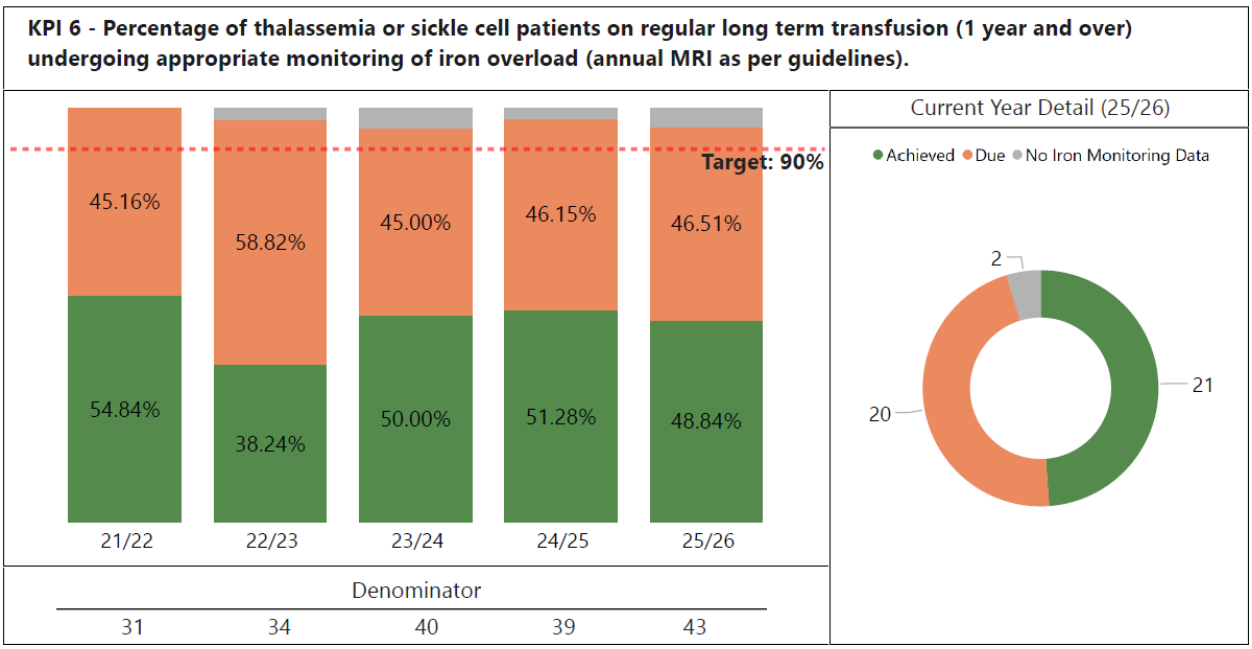


Figure 14: Percentage of thalassemia or sickle cell patients on regular long term transfusion (1 year and over) undergoing appropriate monitoring of iron overload. Results shown for past 5 years.

KPI 7 – 100% of patients with Thalassaemia or Sickle Cell Disease should be offered an annual review.

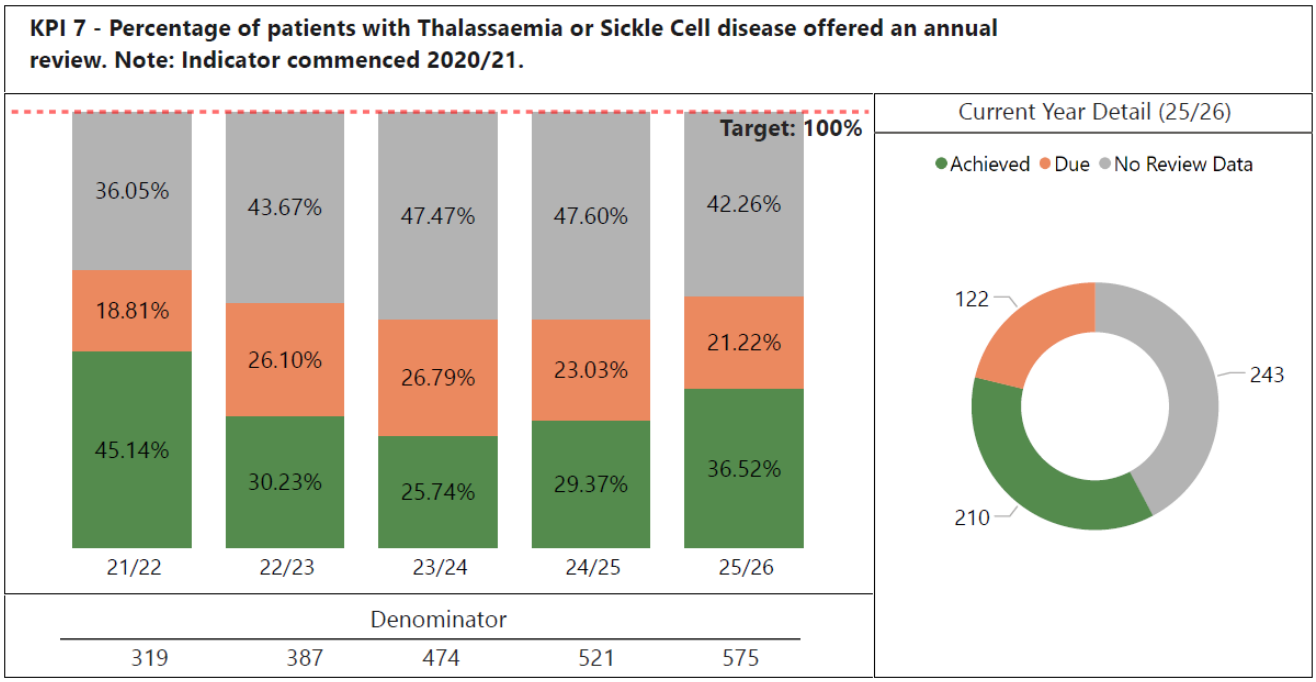


Figure 15: Percentage of patients with thalassemia or sickle cell disease offered an annual review. Results shown for past 5 years.

It is likely that a much higher percentage of KPIs 6 and 7 have been achieved but not recorded on CAS. It is recognised that this needs to be explored further to understand the barriers to data collection.

Looking forward – 2026/27

The Network will undertake a comprehensive strategic needs assessment to inform its workplan over the next 3 to 5 years. This will enable the Network to agree clear, evidence-based, and measurable outcomes. As part of this process, we will assess the needs of the patient population to guide and strengthen future patient engagement activity.

The Network will continue to support the Nursing Sub-Group, Guidance Sub-Groups and Case Discussion Sessions, facilitating regular meetings that provide opportunities for peer support, shared learning, and professional collaboration.

Network business as usual activity:

- Network meetings:
    - SPAH Steering Group
    - Paediatric Guidance Sub-Group
    - Adult Guidance Sub-Group
    - Nursing Sub-Group
    - Case Discussion Sessions
- Management of network communication channels
- Review of network documentation
- Distribution of quarterly patient registry and KPI spreadsheets

Finance

The Network is funded through Public Services Delivery Scotland and operated within its approved budget during 2025/26.