SPAH
Scottish Paediatric and Adult Haemoglobinopathies Network

Annual Report 2024/25

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This document has been prepared by NHS National Services Scotland (NSS) on behalf of SPAH. Accountable to Scottish Government, NSS 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 an NSS 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 health care 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.

Lead Clinician Update

Over the last year the Network team have worked hard to spread the knowledge of how to care for patients with haemoglobinopathies with the development of additional guidelines, educational sessions across different disciplines, and additional resources on the website. The attendance, feedback and number of hits on the website is testament to the desire for this, and we will continue to provide this in the years to come.

Many challenges remain. As a Network we continue to support the clinical services which are struggling to meet the needs of an increasing patient population. Many of the issues are recognised, but the current financial climate is a difficult one in which to increase existing services and add new ones. It is hoped that Scottish Government Review will provide opportunities to address some of these difficulties.

Gene therapies for these conditions are on the horizon and may be potentially transformative for some patients. Whilst they will not be suitable for everyone, the SPAH team will work with the NHS Scotland and the Scottish Government to ensure that suitable patients have access, if and when these treatments are approved.

Despite some difficulties, I believe this Network continues to drive forward the quality of care of patients with these conditions across all of Scotland. I'd like to thank all the SPAH Network members, core team, and patients for enabling us to do so, and look forward to continuing this work next year.

Current position

In light of the ongoing Scottish Government review of national networks, planning has been adapted to focus on core priorities and ensure continuity of essential services. We await further guidance to inform future strategic development

The actions prioritised for SPAH were:

Priority Action	Progress
Engaging with emergency departments to explore standards and improvements	Lead Clinician presented at RCEM Scotland National meeting in Dundee on 16 May 2024. Raising awareness about Sickle Cell in Scotland and the new RCA&E guidelines. Guideline signposted on SPAH website. Network will develop a communication to emergency departments to highlight standards and available resources.
Developing education to support manual red cell exchange.	Two presentations were provided at the SPAH Education Session in September 2024: • Manual red cell exchange for Sickle Cell Disorder • How to perform manual red cell exchange Links to education videos were added to SPAH website and distributed to SPAH stakeholders.
Providing advice on developing and delivering a service for patients in Scotland eligible for transformative therapy to inform planning.	Advisory paper produced by SPAH and shared. SPAH will continue to provide advice as required to support the planning of transformative therapy provision in Scotland.

Out of the 21 BAU objectives outlined in the 2024/25 workplan, 20 were successfully completed. The review of SPAH guidelines and documents in line with the document timetable continues with some incomplete due to limitations in clinical capacity. These guidelines were risk assessed and deemed appropriate to remain on the SPAH website. This objective will be carried forward and prioritised in the 2025/26 workplan.

Highlights

Strategic Plan

The network has built upon the information gathered from a strategic planning session in Perth in January 2024 to develop a long-term vision and a strategic plan setting out how the network will work towards that vision over the next few years. This work was also informed by a survey undertaken to identify what mattered to patients.

The strategic plan was endorsed by the Steering Group on 21 March and sets out how the network will work towards their long-term vision over the next few years. Progressing the strategic plan was scheduled to begin in 2025/26 however the network awaits further guidance to inform strategic development.

Psychology

A questionnaire was issued to stakeholders to scope current psychology provision across Scotland. The findings of the scoping questionnaire were reviewed by the Steering Group at their meeting on 21 March 2025. The paper highlighted the importance of psychological support for patients living with chronic illnesses, particularly those frequently requiring hospitalisation, and the limited access to such support within NHS Scotland. It was clear that many patients experience significant impact on their work and personal relationships due to their health conditions. The importance of addressing psychological needs was recognised in the relevant guidelines for managing sickle cell disease and other related conditions. This is captured within the network's strategic plan.

The availability of qualified psychologists across the country is limited. This creates a challenging situation where the resources may not be accessible.

Case Discussion Meetings

SPAH continued to facilitate peer support for specialists through delivery of 5 case discussion meetings using Teams. There were 20 cases and 2 adverse events discussed across the year with an average attendance of 10 clinicians. This format supports patient care and allows sharing of clinical knowledge.

Website Review

A project to review and update the SPAH website was completed.

The website had nearly 11,059 visitors during 2024/25 and 34,019 views. This evidences the continued requirement for this resource especially when accessing clinical guidelines. The top 10 pages are in the table below:

Content	Views
Home page	19,610
Patient & families	1,396
Adult protocols / guidelines	1,379
News & Events	1,182
Paediatric Protocols/Guidelines	1,120
Professional Zone	1,073
TCD referral form	866
Info leaflets and videos	770
Reports	564
Pathways and referral forms	496

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 over 183%. 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 have identified the need to review the model of care as part of the strategic work plan. This is scheduled to begin in 2025/26 however the network awaits the outcome of the Scottish Government review.

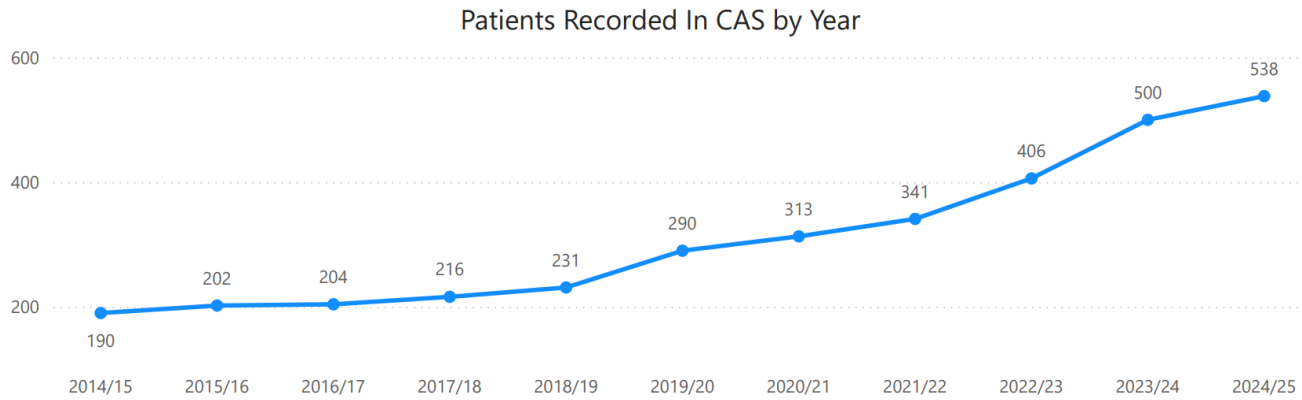

Fig 1: Patients recorded in the Clinical Audit System by Year

Total number of patients by Health Board

It is worth noting that whilst the numbers in the larger health boards continue to increase, the biggest rises are in the smaller health boards who may have been less familiar with these conditions until recently.

Health Board of Residence	20/21	21/22	22/23	23/24	24/25	5 Year % Change
A&A	<5	<5	6	8	15	400.00%
D&G	<5	<5	<5	<5	<5	-100.00%
FIFE	<5	<5	<5	7	8	700.00%
FV	<5	<5	7	13	15	650.00%
GG&C	157	177	189	213	230	46.50%
GRAM	55	56	81	85	88	60.00%
LAN	19	20	24	31	35	84.21%
LOTH	51	55	65	104	111	117.65%
TAY	24	23	31	38	36	50.00%

Fig 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:

Patient Treatment Centre	SICKLE CELL DISEASE	THALASSAEMIA INTERMEDIA	THALASSAEMIA MAJOR
A&A - ADULT	<5		<5
ABERDEEN - ADULTS	47	<5	<5
ABERDEEN - CHILDREN	36	<5	
DUNDEE - ADULTS	18	<5	<5
DUNDEE - CHILDREN	9	<5	<5
EDINBURGH - ADULTS	52	<5	5
EDINBURGH - CHILDREN	49	5	5
FORTH VALLEY	7		<5
GLASGOW - ADULTS	124	9	<5
GLASGOW - CHILDREN	109	13	16
LANARKSHIRE - ADULT	5		

Fig 3: Patients in Scotland by Condition and Treatment Centre

Adult & paediatric population per 100K 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, Forth Valley, Greater Glasgow & Clyde, Grampian, Lanarkshire, Lothian and Tayside.

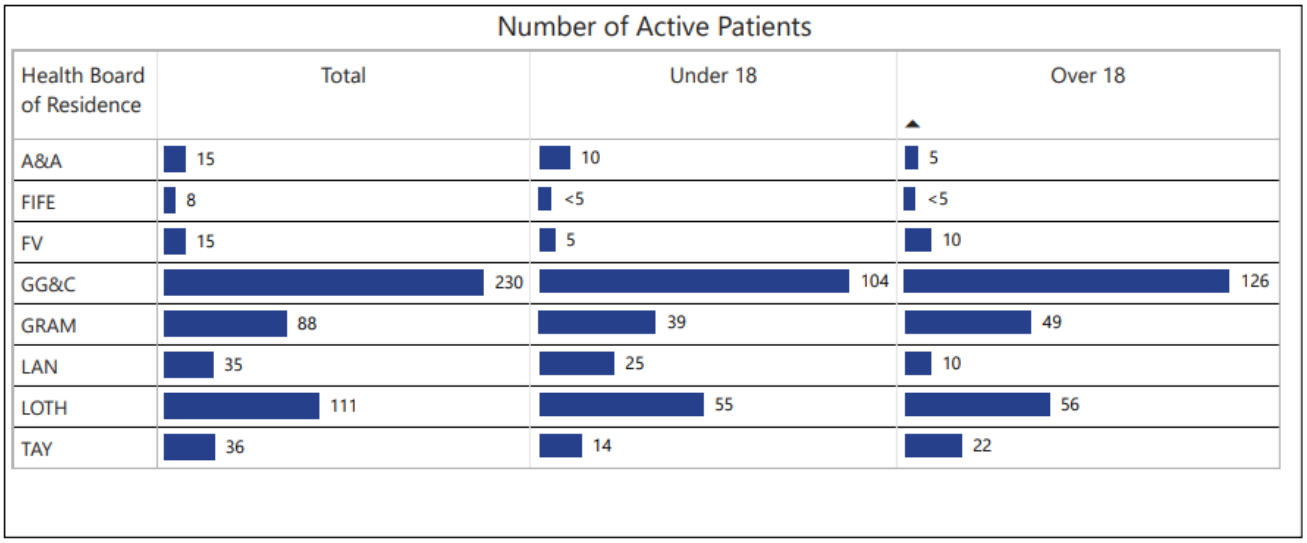

Fig 4: Total number of patients by Health Board

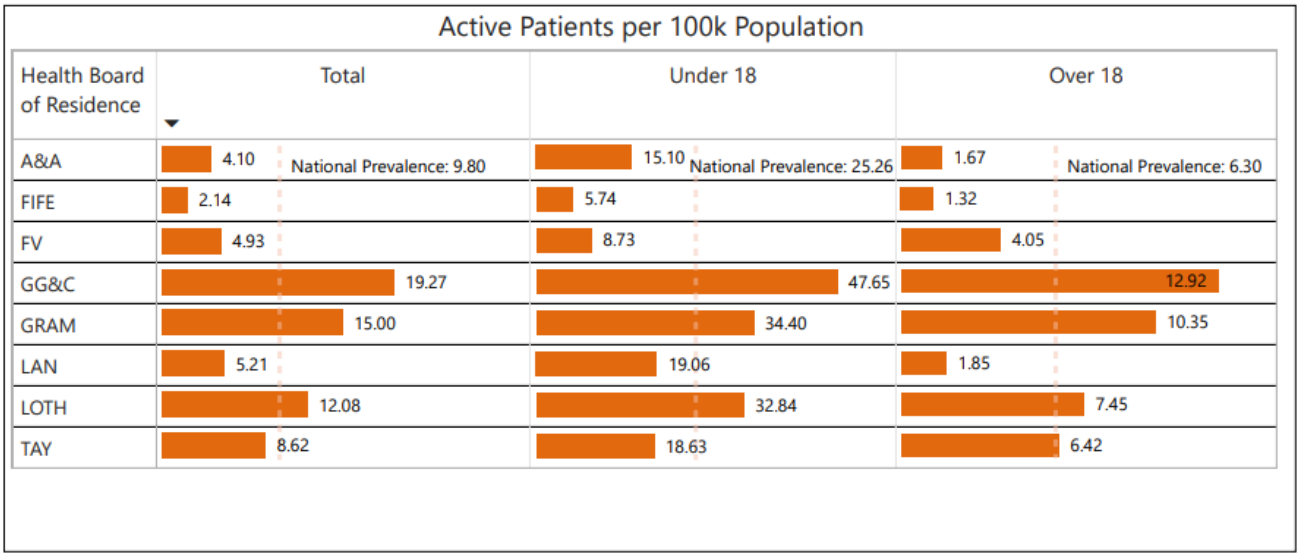

Fig 5: Total number of patients by Health Board per 100k population

Babies identified through newborn screening (NBS)

SPAH in conjunction with the Newborn Screening Laboratories collate data on the number of babies born with haemoglobinopathies. The number of babies identified through screening has seen a significant increase within the last 2 years as evidenced in the graph below creating pressure on paediatric services.

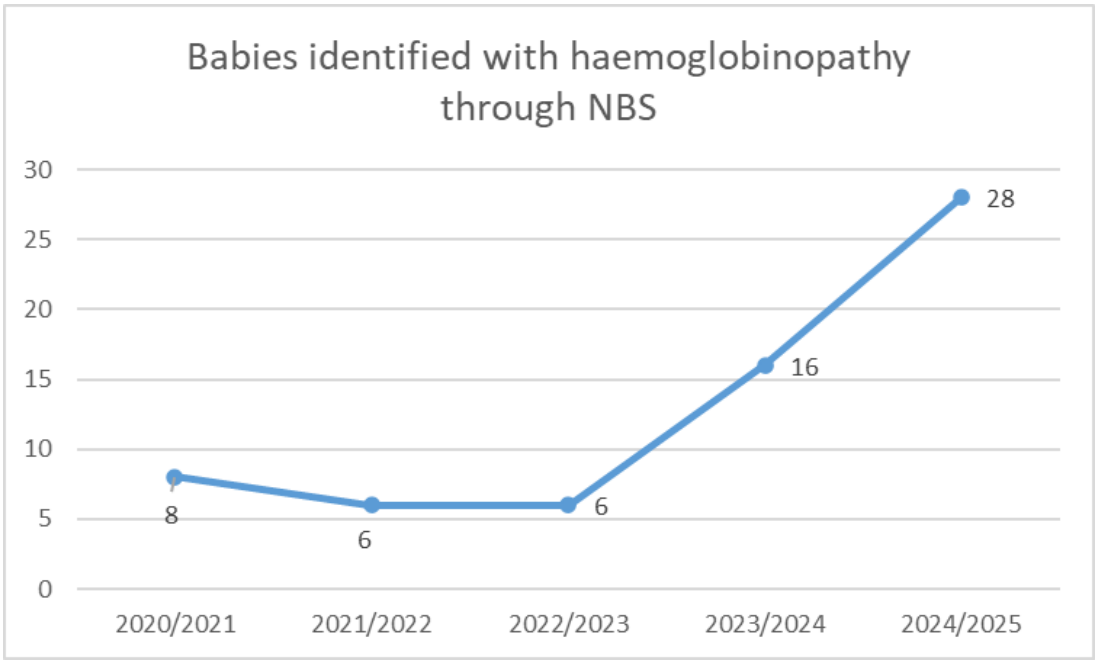

Fig 6: Babies identified through newborn screening over last 5 years

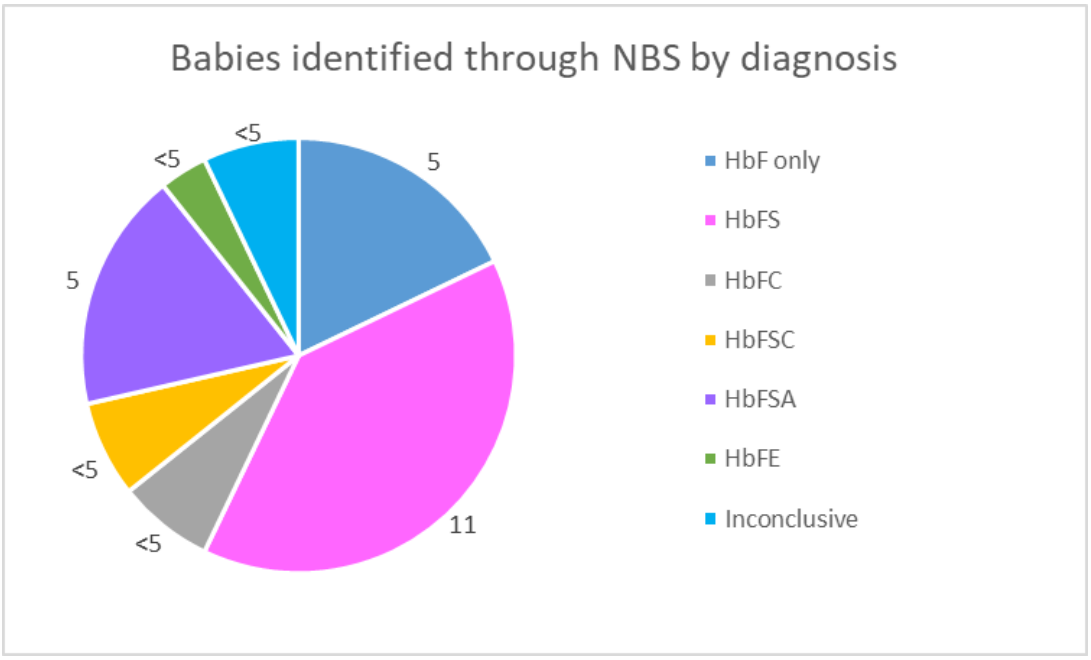

Fig 7: Babies identified through newborn screening by diagnosis (born in 2024/25)

This increase in births has particularly impacted Greater Glasgow & Clyde Health Board who look after 64% of babies born in past 5 years.

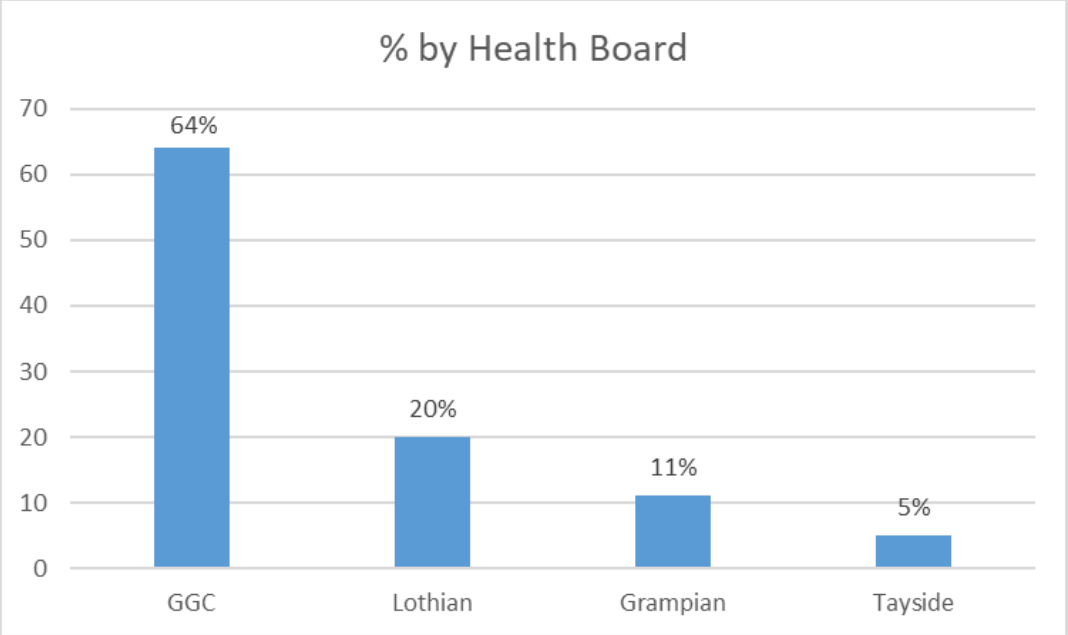

Fig 8: Percentages of babies identified by NBS by paediatric service

Reporting Against SPAH Key Performance Indicators

Measuring performance has once again been an objective for the network during 2024/25. Clinicians have continued to provide data to measure against 7 Key Performance Indicators (KPIs).

The data output for all the KPIs is only as good as the data put in. 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.

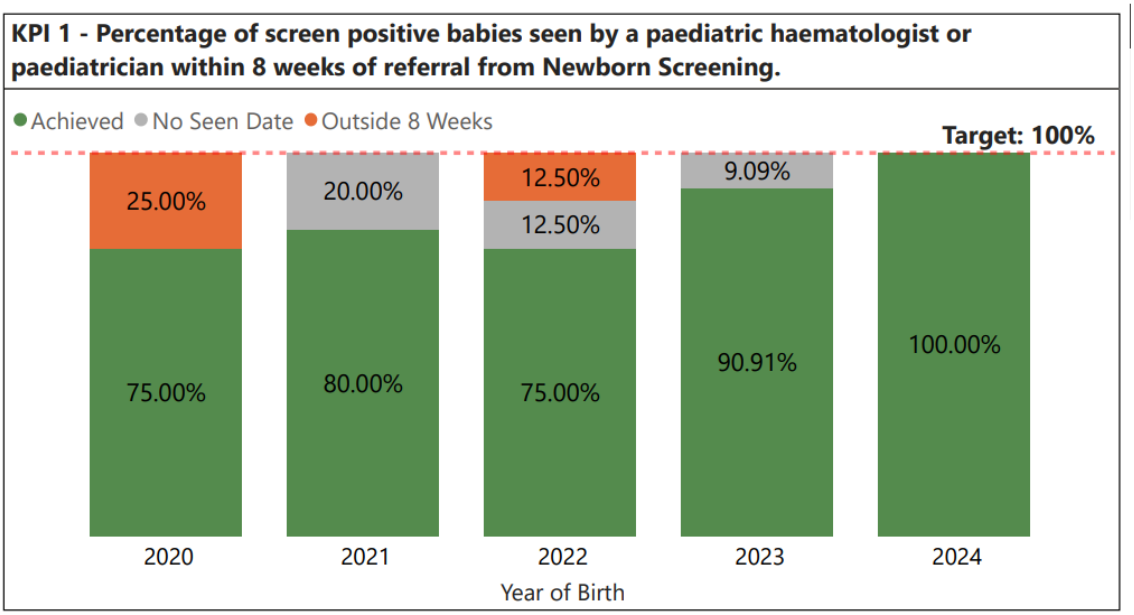

Fig 9: Percentage of screen positive babies seen by a paediatric haematologist or paediatrician within 8 weeks of referral from NBS. Results shown for last 5 years.

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.

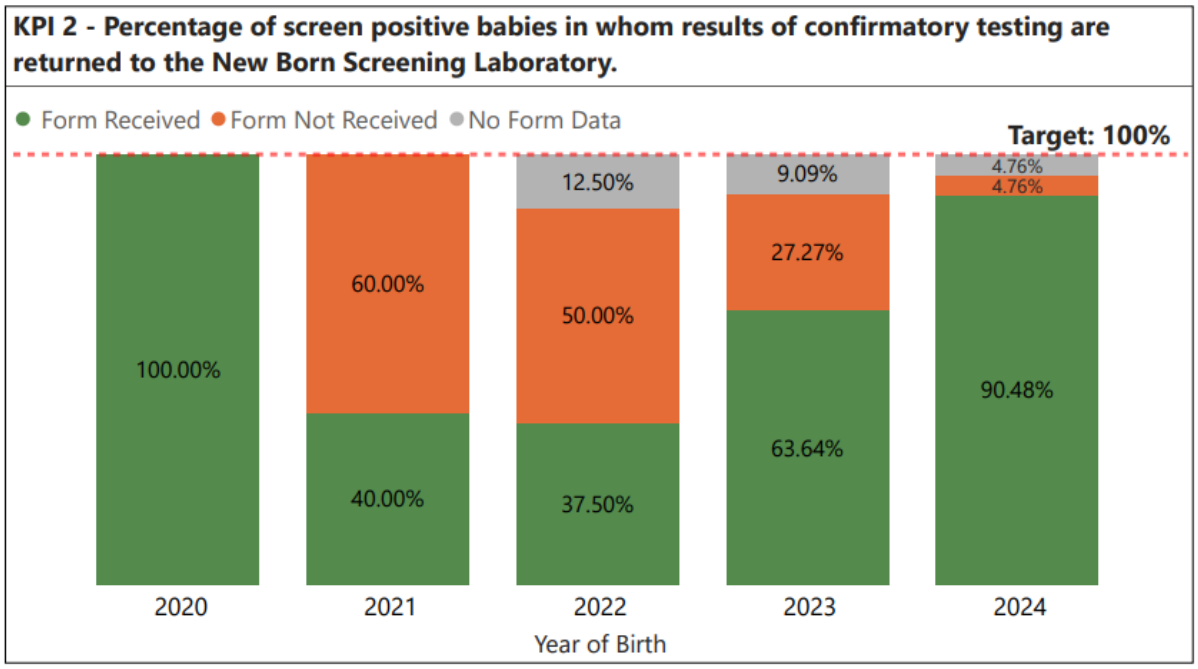

Fig 10: Percentage of screen positive babies in whom results of confirmatory testing are return to the NBS laboratory. Results shown for last 5 years.

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

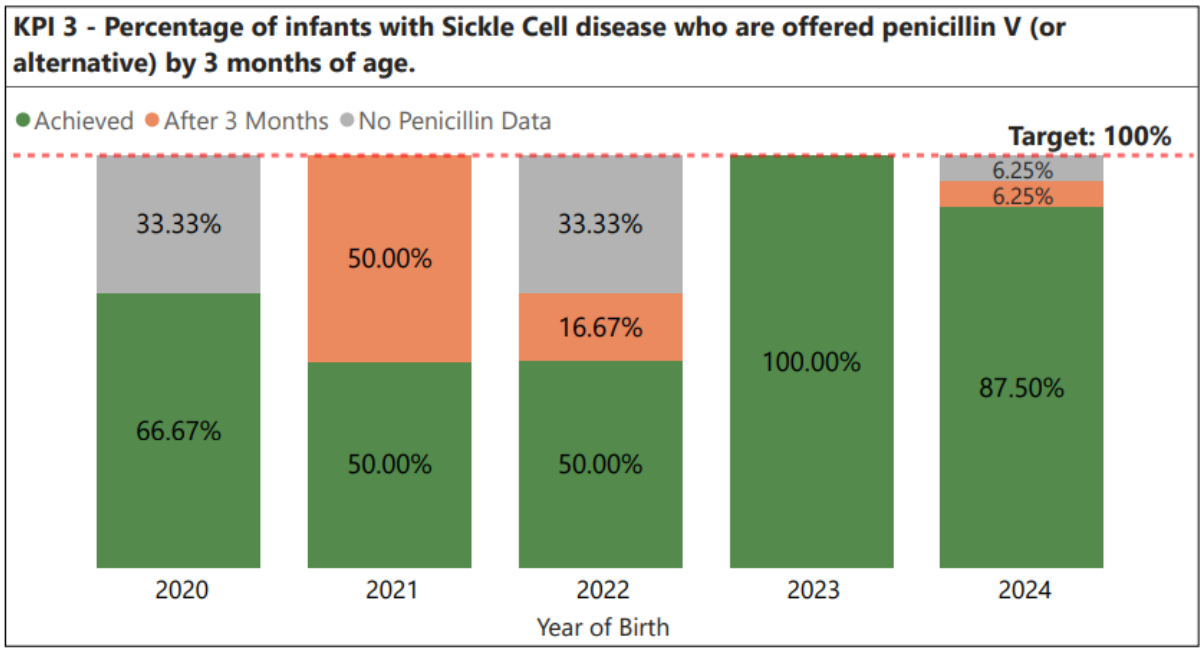

Fig 11: Percentage of infants with SCD who are offered penicillin V (or alternative) by 3 months of age. Results shown for last 5 years.

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

Access to data around vaccinations is recognised as challenging. At the strategic planning event it was agreed that further work was required to better understand the systems used for recording vaccinations and explore if there was a more effective way to access data and information. This was part of the workplan for 2024/25 however was paused due to the Scottish Government review. 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.

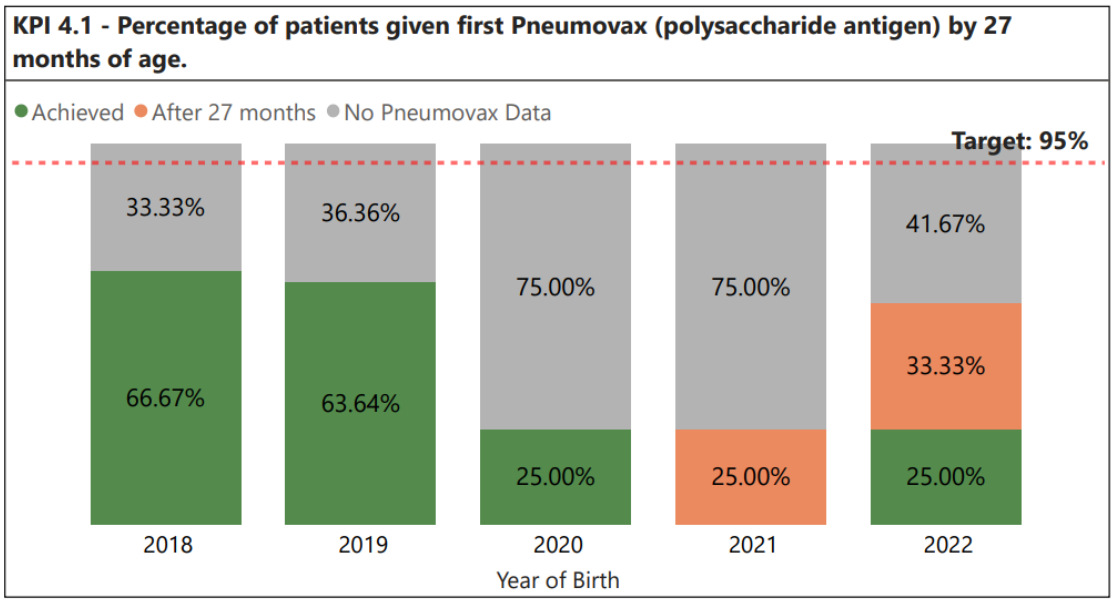

Fig 12: Percentage of patients given first Pneumovax by 27 months of age. Results shown for last 5 years.

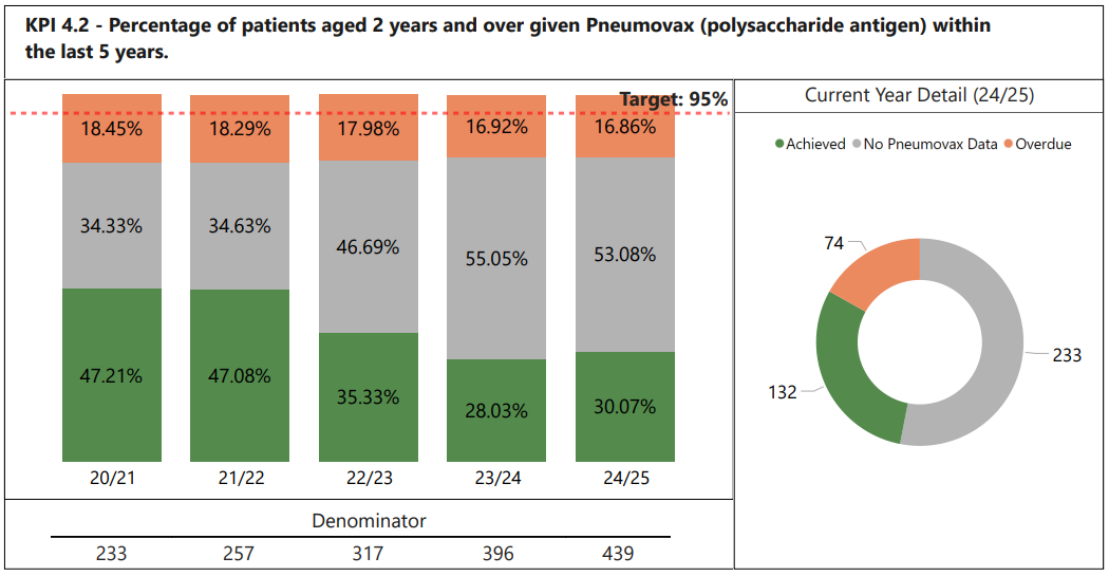

Fig 13: Percentage of patients aged 2 and over given Pneumovax within the last 5 years. Results shown for past 5 years.

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

The TCD service worked hard to catch up on annual scans following the pandemic, however the number of patients continues to increase creating capacity issues around the availability of TCD slots. The network is working with the clinical service and NSD to highlight the importance of this service.

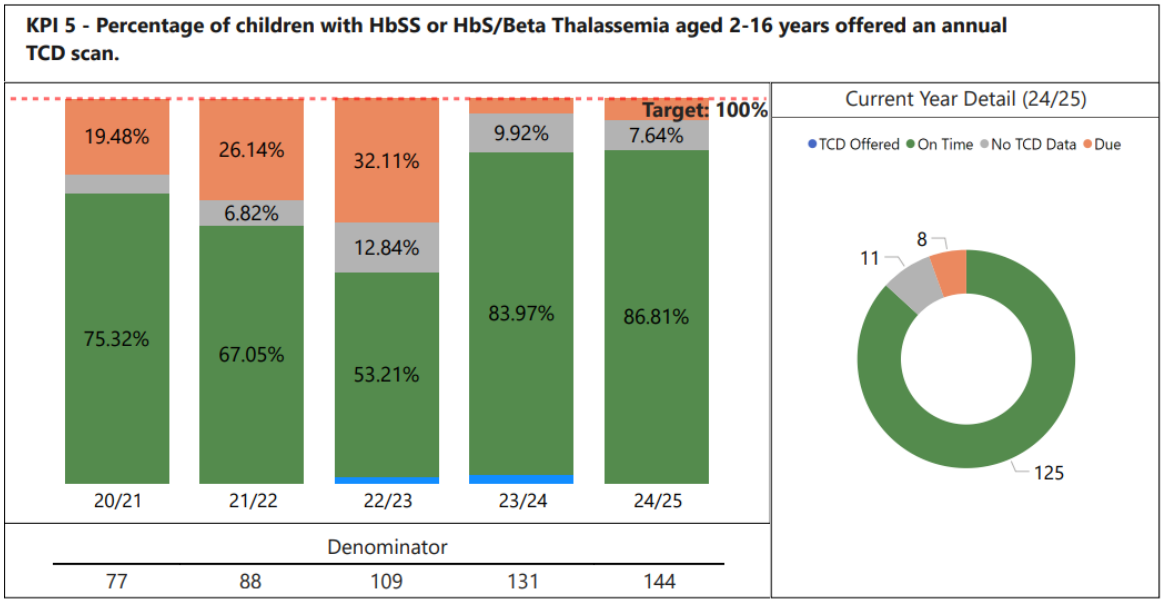

Fig 14: Percentage of children with HbSS or HbS/Beta thalassemia aged 2-16 offered an annual TCD scan. Results shown for past 5 years.

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.

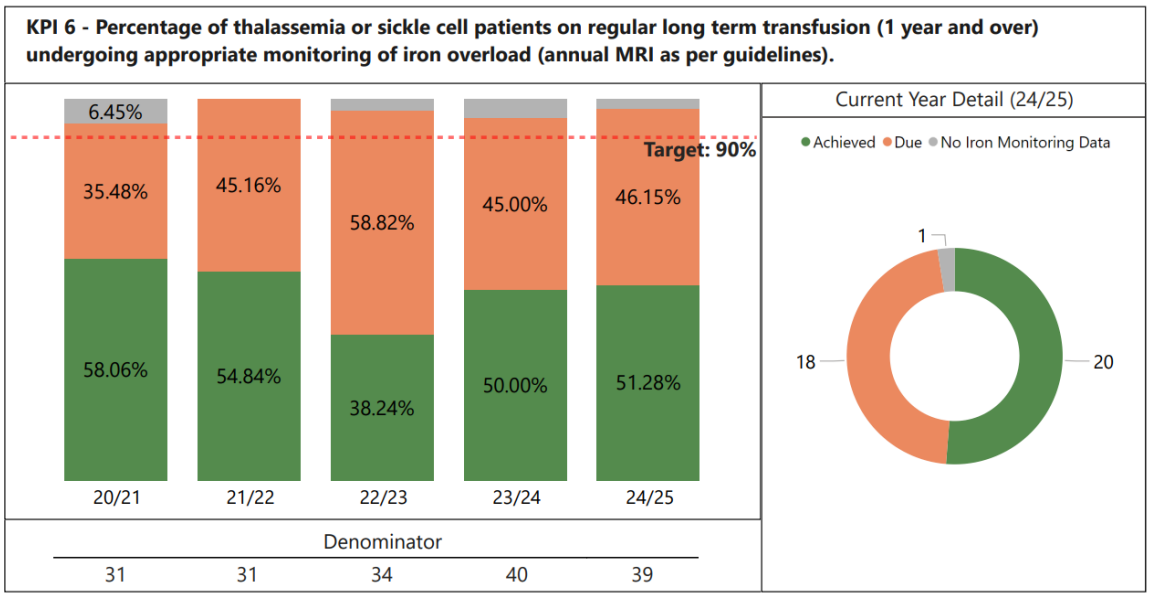

Fig 15: Percentage of thalassemia or sickle cell patients on regular long term transfusion (1 year and over) undergoing appropriate monitoring of iron overload. Results shown for past 5 years.

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

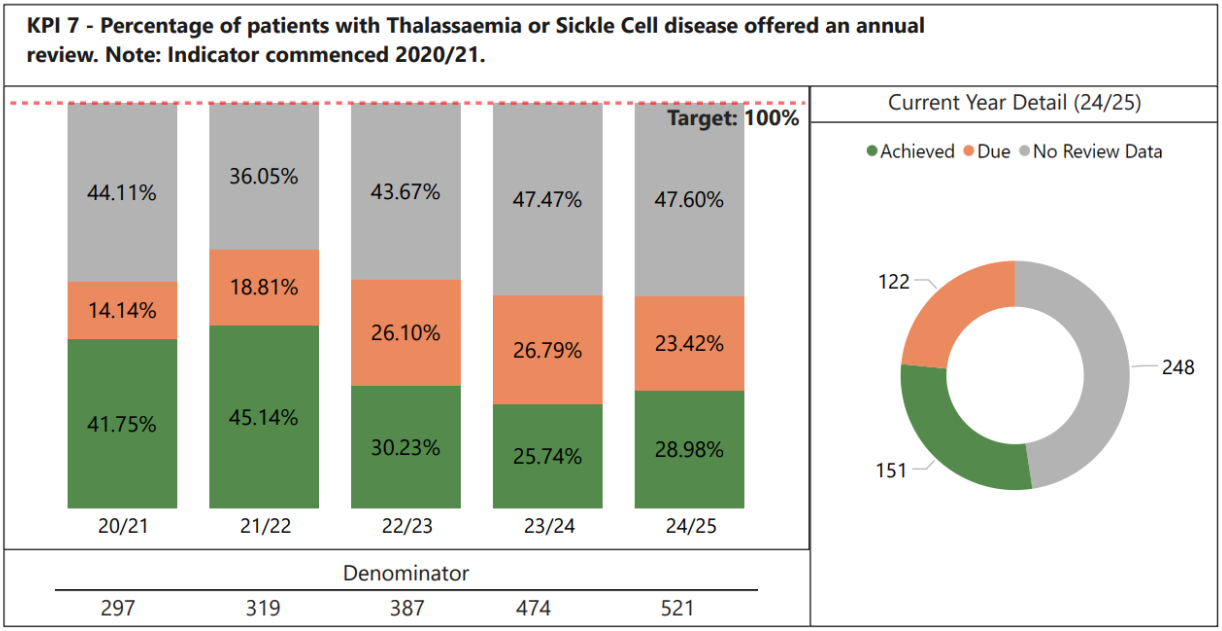

Fig 16: Percentage of patients with thalassemia or sickle cell disease offered an annual review. Results shown for past 5 years.

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 – 2025/26

Due to ongoing review of national networks, networks have been asked to only plan activity for the first two quarters of 2025/26. SPAH have agreed the following activities:

Continued from 2024/25:

- Engaging with emergency departments to explore standards and improvements. Develop a communication to emergency departments to highlight standards and available resources.
- Further scoping work will continue into 2025/26 regarding developing services for patients in Scotland eligible for transformative therapy.

Network business as usual activity:

- Network meetings:
  - SPAH Steering Group
  - Paediatric Guidelines Sub-Group
  - Adult Guidelines 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

Schools Sickle Cell Booklet printing costs £47.48.

Risks and issues

The network recognises the importance of maintaining national coordination in areas such as education, clinical guidance, and quality improvement. Continued support will be essential to sustain these benefits for patients and professionals

Stakeholders have highlighted the importance of maintaining national coordination to sustain improvements in care. Continued support will be essential to build on existing progress and deliver future benefits.