

SPAH
Scottish Paediatric and Adult
Haemoglobinopathies Network

Annual Report
2021/22

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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. Patients are primarily treated in five centres (Aberdeen, Dundee, Edinburgh, Glasgow and Forth Valley), with equity of care supported through the use of standard guidelines and networking amongst the clinicians to share best practice.

Current Position

Understandably NHSScotland's priority during 2021/22 has continued to be to manage the impact of COVID-19 this has seen clinical and other resource diverted from network activity.

Throughout the course of the year the network has undertaken to monitor workplan objectives to minimise the impact on the SPAH community including limiting communications and requests to staff unless the work carried out would directly benefit patients. Projects not requiring the involvement of clinicians have been progressed by the SPAH Core Team.

The network has progressed the majority of workplan objectives. however due to clinician capacity a number are taking longer to complete than expected due to the ongoing COVID-19 pandemic and pressures on the clinical service. Following a directive from the Chief Operating Officer, network activity was paused from December to March, which also had an impact on workplan objectives being progressed. A full work plan update is available on page 12.

Dr Susan Baird, who has been Lead Clinician of the network since 2017, stepped down from her role in June. The network thanks Dr Baird for her leadership and commitment over the past 4 years and is pleased to report that she will continue as an active member of the network. The network was pleased to welcome Dr Louisa McIlwaine to the role of Network Lead Clinician in September.

Lead Clinician Reflections

I have been involved in the SPAH network since it started and have seen the difference that it has made to patients and clinicians. I am therefore very honoured to have the role of lead clinician.

The network supports patient and clinicians in a variety of ways. The SPAH website provides clinicians across Scotland with access to emergency protocols. Similarly, provides a trustworthy source of information for patients and families.

National multidisciplinary meetings support clinicians across Scotland and in the last year, through SPAH, we have developed links with the experts in West London Haemoglobinopathy Coordinating Centre providing expert support.

The patient numbers continue to grow, and the SPAH clinical audit system (CAS) provides a valuable data resource which allows us not only to identify how many patients we have, but also where service development is required. Like any data collection system the information obtained is only as useful as that which is put in. There are barriers to data collection within daily clinical practice, but I hope to focus on certain areas that can influence patient care.

The network has made a big difference in its first decade, but there remain many challenges, some of which we are hoping to address in the next few years. The transition from paediatric to adult care is not easy and involves not only a change in caregiver but often hospital. This is a scary and challenging time and we are looking to involve our young patients to help us identify where improvements can be made. Increasingly some of our patients are moving away from the big cities, and so ensuring every health board in Scotland has designated links to the SPAH guidelines, MDTs and other resources is the aim of our national mapping exercise, which recently started.

Teams has allowed some essential educational sessions to continue during the pandemic but we look forward to the time when we can resume the patient/parent education meetings. It had been hoped that these would be something that could be done in person this year, but with the threat of covid still around and the vulnerability of the patient group we have decided to explore whether some form of online activity would be of interest.

Finally, this network would not be able to function without the support of the Programme Team and I wish to extend my gratitude to them for their hard work and support over the last year.

Highlights

Scottish Ambulance Service & Improvements to Pre-Hospital Care: The network is continuing its collaboration with the Scottish Ambulance Service with work underway to develop a hand held patient alert card containing key information about their condition and how it should be managed. A patient information leaflet on how to call an ambulance to highlight the needs of a patient experiencing a sickle cell crisis has also been drafted and considered by stakeholders.

Education and information: This remains a priority for the network, with the aim to continue to build a range of resources for both professionals and other stakeholders. Current resources are easily accessible through the website and provided at clinics and the Nurse Sub-Group is now well established with regular meetings to review patient information as well as provide peer support and education.

Susan Baird presented on haemoglobinopathies at the expertise to Royal College of Physicians of Edinburgh Event on 27 April 2021 and there have been various local hospital educational meetings run by SPAH members to improve patient care.

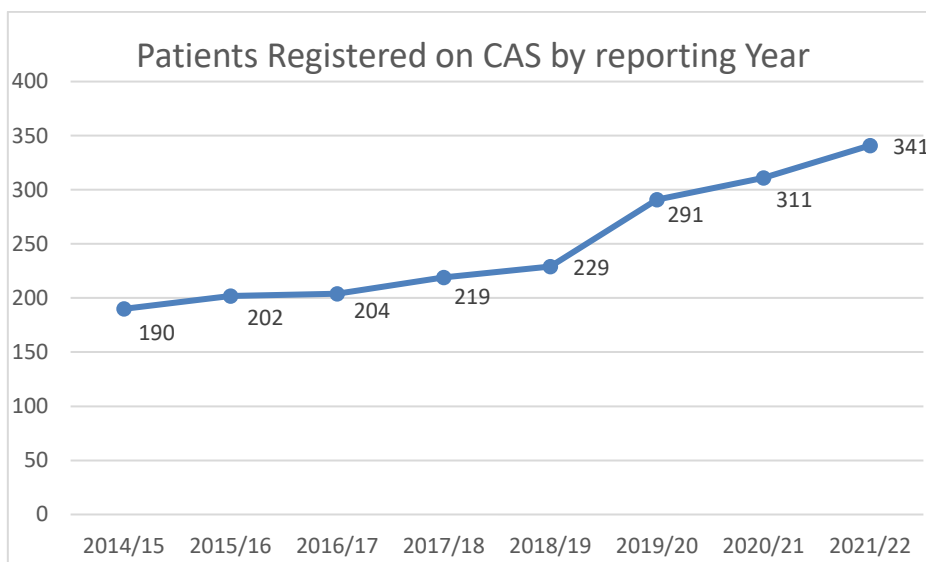
Adult Ferriscan Service: The Ferriscan service previously provided to all adult patients at risk of transfusion related iron overload in Scotland at two locations (Grampian and Forth Valley) is no longer available. To mitigate the impact of Ferriscan being unavailable a short term pathway has been developed supporting referral of adult patients for scanning at the Queen Elizabeth University Hospital in Glasgow which commenced in May 2021. The network is continuing to explore the feasibility of scans being provided locally in the NHS.

Review of Services: A survey has been circulated to gain feedback from haematologists in relation to current services and to raise awareness of the network and availability of SPAH protocols. SPAH has also enquired with Health Board areas who do not have patients registered on the Clinical Audit System to ensure their patients are being added to the database. The aim is to identify interested clinicians in each Health Board and the findings will be used to identify any improvements to be taken forward.

Patients with Haemoglobinopathies registered on the National Clinical Audit System (CAS)

The Clinical Audit System continues to be the national register for SPAH. There are a total of 333 active follow up patients currently registered on CAS, an increase of 30 patients from 2020/21.

Patients have been registered on CAS since 2013 with annual figures reported since 2014/15 showing a continued increase in the number of patients living with haemoglobinopathies in Scotland.

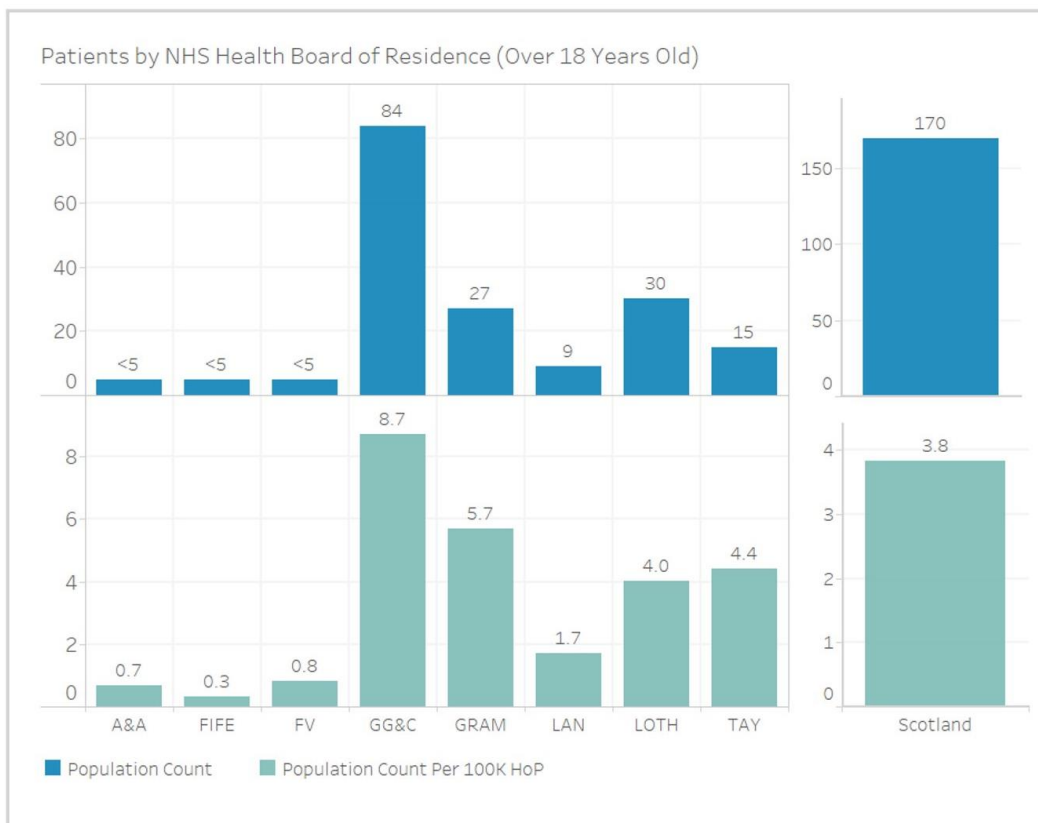
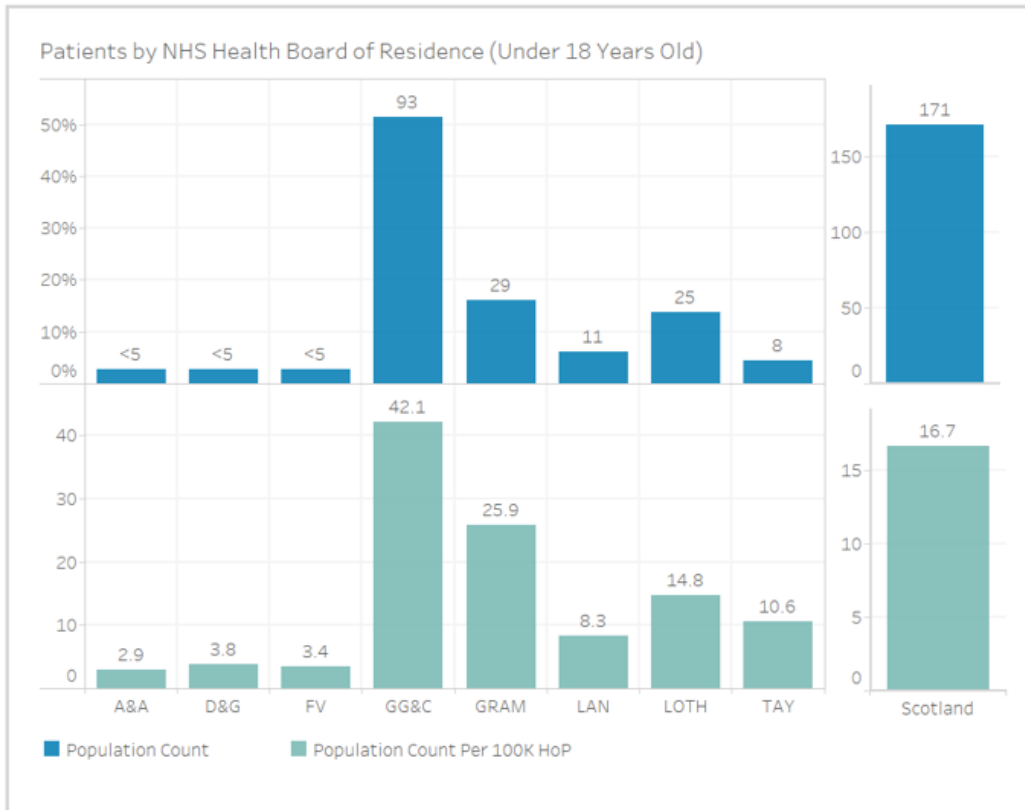


The largest group is patients with sickle cell disease, with the distribution across Scotland shown in the tables below:

Patients and Conditions by Treatment Centre

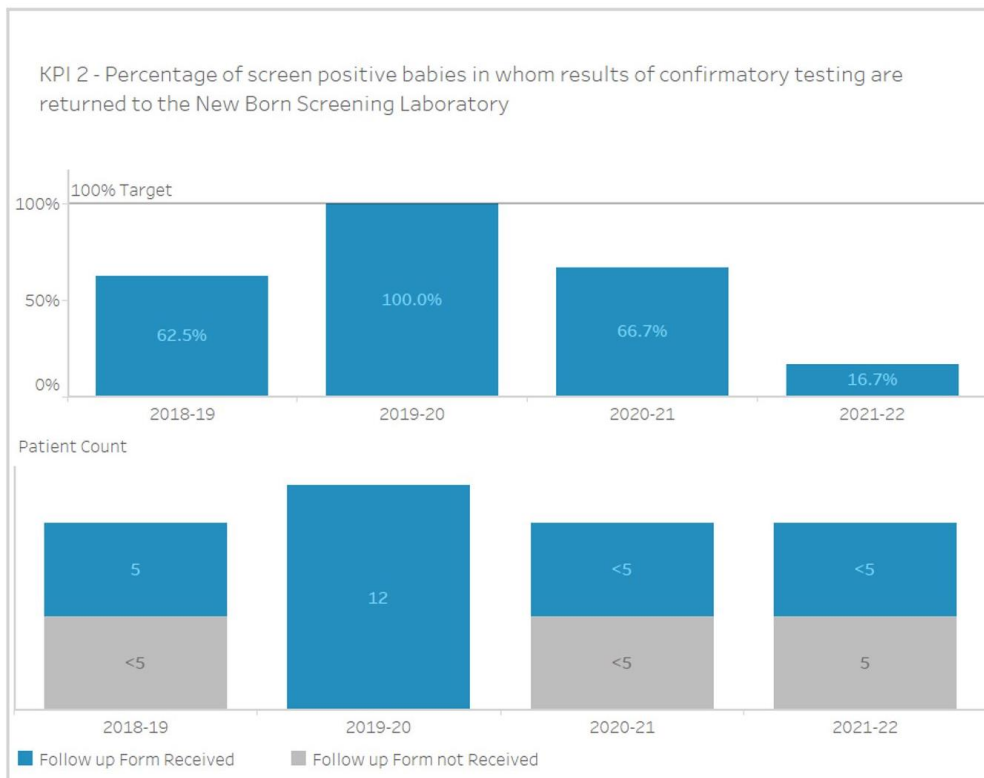
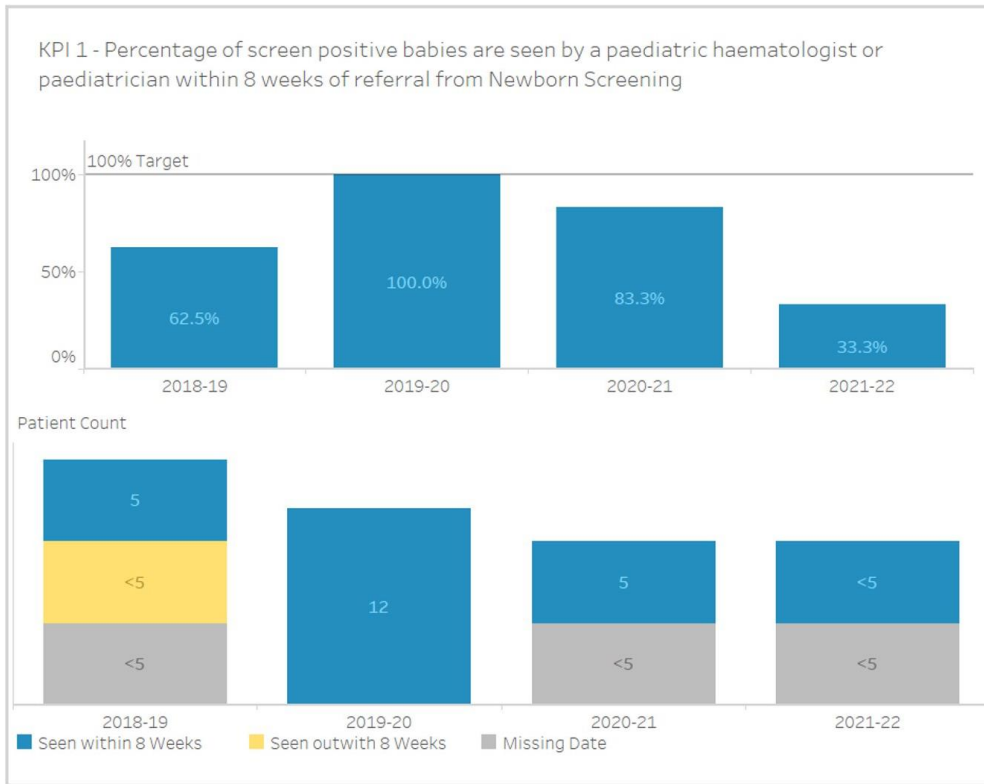
	SICKLE CELL DISEASE	THALASSAEMIA INTERMEDIA	THALASSAEMIA MAJOR
ABERDEEN - ADULTS	23	<5	<5
ABERDEEN - CHILDREN	23	<5	
DUNDEE - ADULTS	12	<5	<5
DUNDEE - CHILDREN	<5	<5	<5
EDINBURGH - ADULTS	27	<5	<5
EDINBURGH - CHILDREN	18	<5	6
FORTH VALLEY	<5		
GLASGOW - ADULTS	81	8	<5
GLASGOW - CHILDREN	85	13	11

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.

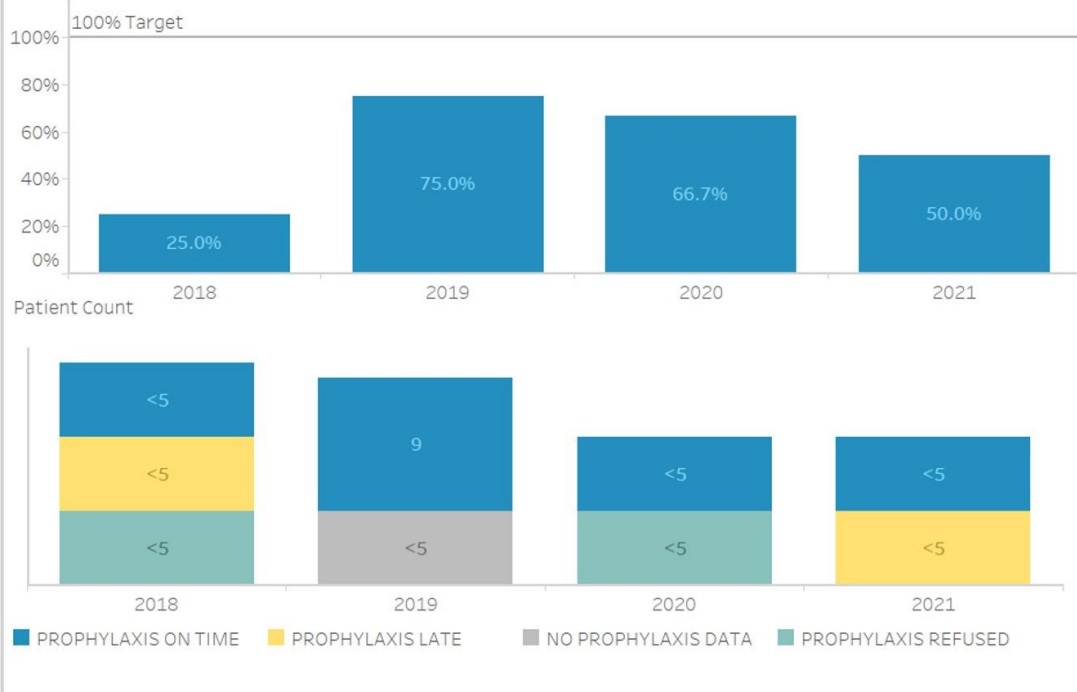


Reporting Against SPAH Key Performance Indicators

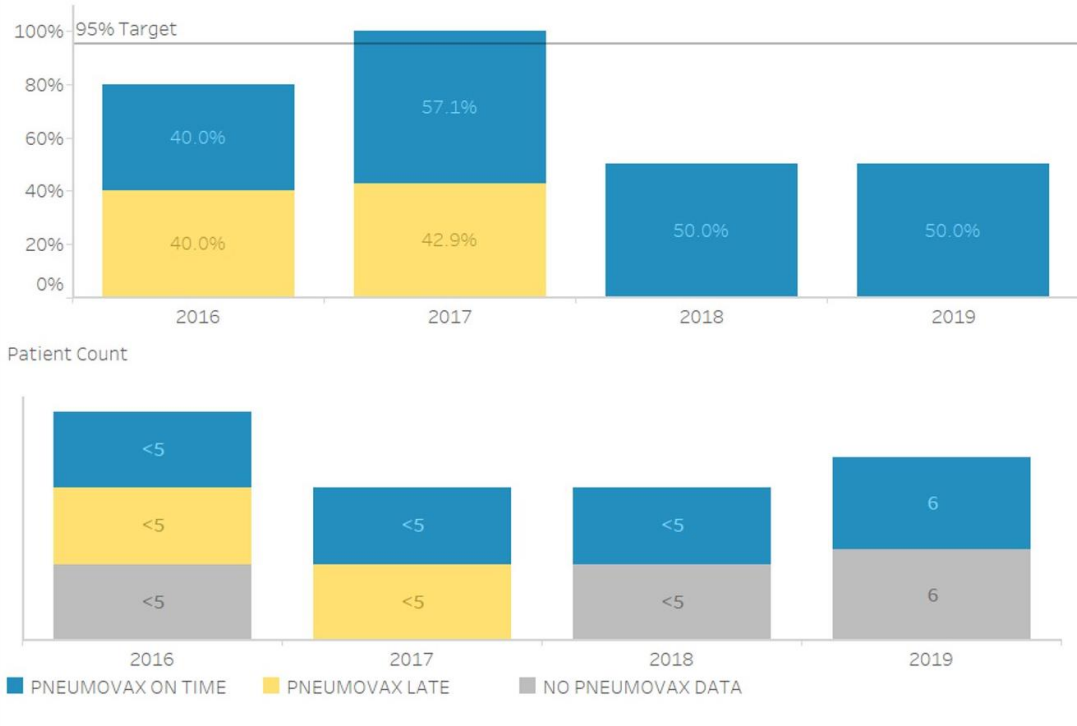
Measuring performance has once again been a major objective for the network during 2020/21. Clinicians have continued to provide data to measure against 7 Key Performance Indicators (KPIs). KPI data which is available within CAS is provided below.



KPI 3 - Percentage of infants with Sickle Cell disease are offered penicillin V (or alternative) by 3 months of age

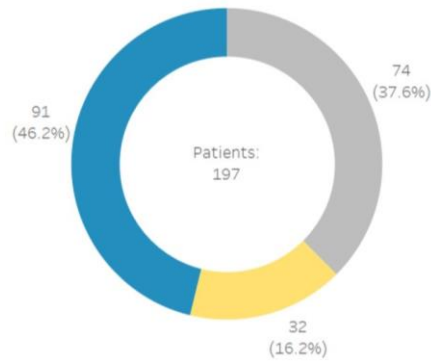


KPI 4.1 - Percentage of patients should be given first Pneumovax (polysaccharide antigen) by 27 months



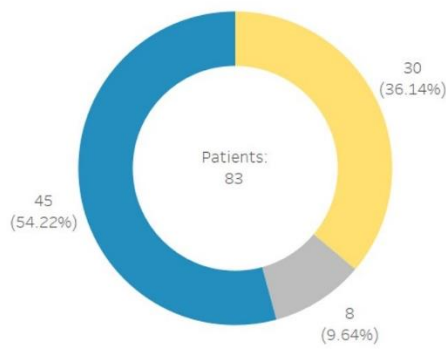
KPI 4.2 - 95% of patients with Sickle Cell disease should be offered Pneumovax (polysaccharide antigen) 5 yearly from 7 Years and 3 months of age

■ NO PNEUMOVAX DATA
 ■ PNEUMOVAX LATE
 ■ PNEUMOVAX ON TIME



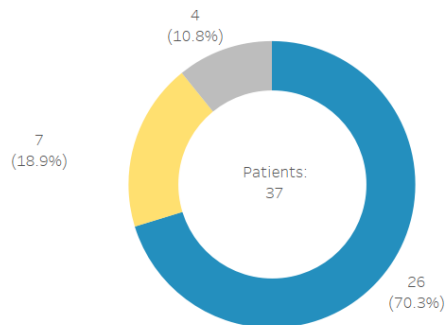
KPI 5 - Percentage of children with HbSS or HbS/Beta thalassemia aged 2-16 years offered an annual TCD scan

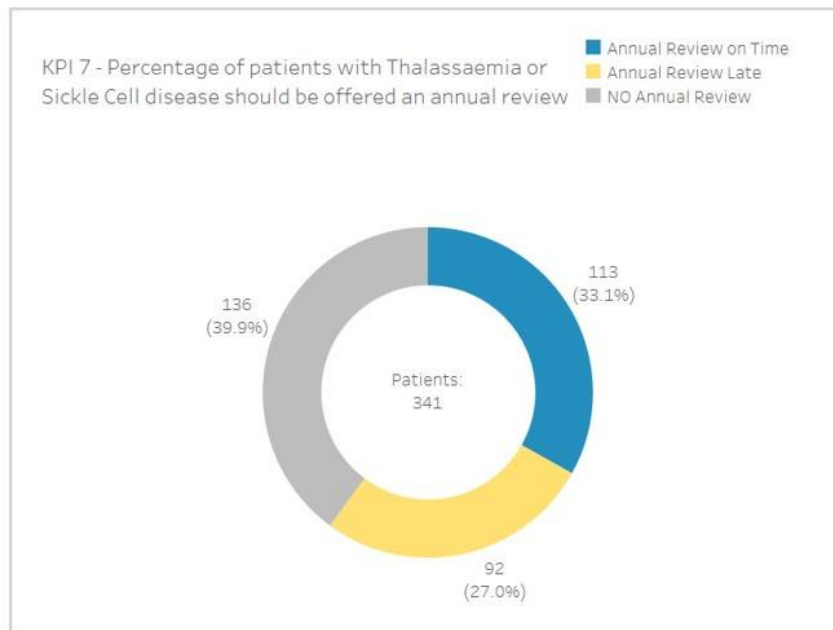
■ LATE TCD PROVIDED
 ■ NO TCD DATA
 ■ TCD ON TIME



KPI 6 - 90% of thalassemia and sickle cell patients on regular transfusion undergoing appropriate monitoring of iron overload (annual MRI as per guidelines)

■ Iron Monitoring ON TIME
 ■ Iron Monitoring LATE
 ■ NO Iron Monitoring Data





Discussion

It is recognised by the clinicians that much of the late or absent KPI data relates to not returning the information to the SPAH team due to clinical pressures rather than reviews and assessments not being undertaken. It is however clear that improvement in data returns in the future is required to ascertain that this is true.

There has been a true reduction in Transcranial Doppler scanning and annual review assessments due to Covid 19 and the restrictions on clinical activity. The TCDs and reviews that have been undertaken have been prioritised for the highest risk groups, and work is ongoing to catch up on the rest.

Exceptions

The following objectives were not delivered as, given the situation caused by the pandemic, the network was keen to minimise the burden on clinicians.

Patient/Family event: All face to face events were cancelled for 2021/2022.

SPAH paediatric bone marrow transplant referral pathway: this was not progressed during 2021/22 and has been carried forward to 2022/23 workplan.

Time to analgesia audit: this was not progressed during 2021/22 and due to clinician capacity will not be carried forward to the 2022/23 workplan however will be discussed again for future years.

Website

The table below highlights the traffic through the website with nearly 15000 hits on the homepage. It is encouraging that the awareness of this site is spreading.

ID	Title	Visits
1	Home Page	14,751
2	Newsletters	650
3	Patients and Families	634
4	Transition	610
5	News	607
6	Protocols/Guidelines Group (Paediatric)	590
7	Protocols/Guidelines Group (Adult)	581
8	News & Events	574
9	Clinical Audit System (CAS)	556
10	Pathways/Flowcharts	544

Finance

The Network has had no financial spend during this reporting period.

Looking Forward

Over the course of 2022/23 the programme of work will include:

- Development and Review of Guidelines/protocols & pathways
- SAS Project: Calling an ambulance patient leaflet and Patient Alert Card
- Paediatric transplant referral pathway development
- Phase 2 - Review of Regional Adult Services
- Parent/Family Event
- Provision of Adult Ferriscan
- SPAH response to the No One's Listening Report
- Review transition between Paediatric & Adult Services
- MDT Meeting Management

The draft workplan for 2022/23 is available in Appendix 2 on Page 17.

Appendix 1 – Annual Business Plan 2021-22

Service Delivery Plan

Core principles	Description of Work	Current status	Start Date:	End date:	RAG Status
Service Development and Delivery	Develop a model for a more consistent communication pathways and linkage between antenatal screening, newborn screening and paediatrics.	Questionnaire has been created to be circulated to establish a baseline of current communication between Pregnancy and Newborn Screening colleagues before consideration is given to developing a Scottish Communication Pathway between the two.	01/06/2021	01/02/2022	G
Service Development and Delivery	Continue Quality Improvement Project collaboration between Scottish Ambulance Service and SPAH including: development of patient information leaflet and patient alert card.	Content of alert card agreed by Steering Group. Arrangements to be made for printing. Patient information leaflet has been drafted and shared with lead clinician prior to forwarding to SAS for feedback.	02/06/2021	31/12/2021	G
Service Development and Delivery	Scope provision of adult Ferriscan across Scotland.	Susan Baird met with Lothian Adult Radiology Team regarding setting up Ferriscan service locally. Funding to be resolved. Meeting to be scheduled with Catriona Johnson to discuss. Numbers of patients who require annual Ferriscan to be determined.	01/05/2021	30/11/2021	G
Service Development and Delivery	Service Mapping Phase 1 – Review of Services	Questionnaire circulated to Scottish Haematologists and results will be collated to develop a service map for Scotland and to explore if there are patients in other HB areas who are not currently registered on CAS.	1/09/2021	01/12/2021	B
Service Development and Delivery	Develop SPAH paediatric bone marrow transplant referral pathway.	This objective was not progressed during 2021/22. CARRIED FORWARD TO 2022/23	01/10/2021	31/03/2022	N/A
Audit and Continuous Quality Improvement	Time to analgesia audit.	Following a previous “time to analgesia” audit in RHC (patients with sickle cell who presented with pain should receive analgesia within 30 minutes of presentation) a flowchart had been developed with the purpose to improve practice. Due to clinician capacity this objective was not progressed during 2021/22 and will be paused until advised that there is capacity to progress.	01/08/2021	30/09/2021	N/A

Audit and Continuous Quality Improvement	Explore benchmarking opportunities with the rest of the UK and develop a benchmarking plan.	Comparison of KPIs being explored with West London HCC	01/09/2021	31/03/2022	A
Service Development and Delivery	Review transition between Paediatric & Adult Services.	Project has been initiated and discussed at Nursing Sub-Group Meeting. Collation of retrospective data to be considered as this has not been taking place due to clinician capacity.	01/10/2021	31/03/2022	A

Business as Usual Plan

Core principles	Description of Work	Current status	Start Date:	End date:	RAG Status
Stakeholder Communication and Engagement	Maintain and review the content of the website to ensure it is accurate and up to date.	Banner has been updated with new design element.	01/04/2021	31/03/2022	C
Effective Network Structure and Governance	Lead Clinician Recruitment	Dr McIlwaine appointed on 1 September. Future backfill arrangements will continue to be explored.	02/04/2021	31/08/2021	C
Effective Network Structure and Governance	Core Team Meetings	Fortnightly dates in diary for core team meetings.	01/04/2021	31/03/2022	C
Education	Contribute haemoglobinopathies expertise to Royal College of Physicians of Edinburgh Event.	Dr Baird presented at meeting on 27th of April.	01/04/2021	01/04/2021	C
Effective Network Structure and Governance	2020/21 Annual Report	Completed	01/04/2021	31/05/2021	C
Effective Network Structure and Governance	Organise and host bi-monthly Multidisciplinary meetings that facilitates professionals from Scotland and Ireland to engage.	Bi-monthly meetings are well attended with 8 cases presented for discussion during 2021/22.	01/04/2021	31/03/2022	C
Stakeholder Communication and Engagement	Produce Newsletters to share with colleagues in Scotland and available from the SPAH website	Newsletter drafted.	01/10/2021	31/01/2022	R

Audit and Continuous Quality Improvement	Deliver audit programme against key performance indicators in line with the audit timetable.	Quarterly reports issued and data presented within Annual Report.	01/04/2021	31/03/2022	C
Effective Network Structure and Governance	Steering Group Meetings	SG meetings held on 11 June 2021 17 September 2021 January meeting postponed in line with request from Chief Operating Officer to focus on COVID-19 activity.	01/04/2021	31/03/2022	C
Education	Promote link to the PHE module and SPAH website education by cascading to Lead Midwives through links with Scottish Perinatal Network.	Link circulated.	01/07/2021	31/03/2022	C
Audit and Continuous Quality Improvement	Audit and Data Sub-Group Meetings	Meeting held on 26 August.	01/04/2021	31/03/2022	C
Audit and Continuous Quality Improvement	Nursing Sub-Group Meeting	Meetings held on: 30 April 2021 8 September 2021	01/04/2021	31/03/2022	C
Effective Network Structure and Governance	Publish Annual Report on Website	Completed	01/09/2021	30/09/2021	C
Stakeholder Communication and Engagement	2021/22 Mid Year Report	Submitted	01/10/2021	31/10/2021	C
Stakeholder Communication and Engagement	Adult Guideline & Pathway Review	Slight slippage due to clinician capacity however meetings have taken place and review of documentation continuing.	01/07/2021	31/03/2022	A
Service Development and Delivery	Paediatric Guideline & Pathway Review	Slight slippage due to clinician capacity however meetings have taken place and review of documentation continuing.	01/04/2021	31/03/2022	A
Service Development and Delivery	Review of Patient Leaflets	Slight slippage due to clinician capacity. Timetable for review available.	01/04/2021	31/03/2022	A

Stakeholder Communication and Engagement	Organise and host a Family Event working with patients/carers to develop programme.	On hold due to pandemic and advice regarding in face to face events.	01/01/2022	31/03/2021	R
Audit and Continuous Quality Improvement	2022/23 Workplan Objectives		01/01/2022	31/03/2021	C

Appendix 2 – Draft Annual Business Plan 2022-23

Service Delivery Plan

NSS Strategic Objectives	Description of Work	Current status	Start Date	End date	RAG Status
Improving the way we do things	Develop a model for a more consistent communication pathways and linkage between antenatal screening, newborn screening and paediatrics.		01/04/2022	31/03/2023	
Customer at the heart	Continue Quality Improvement Project collaboration between Scottish Ambulance Service and SPAH including: Development of Patient Information Leaflet. Print and distribute patient alert cards.		01/04/2022	31/03/2023	
Customer at the heart	Scope provision of adult Ferriscan across Scotland.		01/04/2022	31/03/2023	
Increasing our service impact	<ul style="list-style-type: none"> •Service Mapping Phase 2 – identify and encourage a haematology expert with an interest in haemoglobinopathies in each health board area and if required by District General Hospital. • Raise awareness of SPAH Network and availability of SPAH protocols. • Review communication with haematology departments in Scottish Health Boards. Updating non MDT/SG haematologists. • Data from CAS to identify numbers and age patients due to transition to adult services by HB and DGH. 		01/04/2022	31/03/2023	
Increasing our service impact	Develop paediatric bone marrow transplant referral pathway.		01/04/2022	31/03/2023	
Improving the way we do things	Explore benchmarking opportunities with the rest of the UK and develop a benchmarking plan.		01/04/2022	31/03/2023	
Improving the way we do things	Review transition between Paediatric & Adult Services.		01/04/2022	31/03/2023	
Customer at the heart	Response to No-one's listening report		01/04/2022	31/03/2023	
Improving the way we do things	Document Management Project		01/04/2022	31/03/2023	
Improving the way we do things	Management of MDT Meetings		01/04/2022	31/03/2023	

Business as Usual

NSS Strategic Objectives	Description of Work	Current status	Start Date	End date	RAG STATUS
Customer at the heart	Maintain and review the content of the website to ensure it is accurate and up to date.		01/04/2022	31/03/2023	
Improving the way we do things	Core Team Meetings		01/04/2022	31/03/2023	
Improving the way we do things	Steering Group Meetings		01/04/2022	31/03/2023	
Increasing our service impact	Nursing Sub-Group Meeting		01/04/2022	20/04/2022	
Increasing our service impact	Review Communications Strategy - Review Date March 2022.		01/04/2022	31/05/2022	
Improving the way we do things	Audit and Data Sub-Group Meetings		01/05/2022	27/05/2022	
Improving the way we do things	2020/21 Annual Report		01/04/2022	31/05/2022	
Improving the way we do things	Organise and host monthly Multidisciplinary meetings that facilitates professionals from Scotland and Ireland to engage.		01/04/2022	31/03/2023	
Customer at the heart	Produce two Newsletters (summer and winter) to share with colleagues in Scotland and available from the SPAH website		01/04/2022	31/03/2023	
Improving the way we do things	Deliver audit programme against key performance indicators in line with the audit timetable.		01/04/2022	31/03/2023	
Improving the way we do things	Audit and Data Sub-Group Meetings		01/05/2022	27/05/2022	
Increasing our service impact	Promote link to the PHE module and SPAH website education by cascading to Lead Midwives through links with Scottish Perinatal Network.		01/07/2022	31/07/2022	
Increasing our service impact	Write article for Scottish Perinatal Network Newsletter.		01/07/2022	31/07/2022	
Customer at the heart	Publish Annual Report on Website		01/04/2022	31/03/2023	

Customer at the heart	2021/22 Mid Year Report		01/04/2022	31/03/2023	
Improving the way we do things	Adult Guideline & Pathway Review (see separate spreadsheet)		01/04/2022	31/03/2023	
Improving the way we do things	Paediatric Guideline & Pathway Review (see separate spreadsheet)		01/04/2022	31/03/2023	
Customer at the heart	Review of Patient Leaflets (see separate spreadsheet)		01/04/2022	31/03/2023	
Increasing our service impact	SpR Education Event		01/04/2022	31/03/2023	
Improving the way we do things	Teenagers/Young Adults Event		01/04/2022	31/03/2023	
Increasing our service impact	2022/23 Workplan Objectives		01/04/2022	31/03/2023	