Scottish Paediatric & Adult Haemoglobinopathies Network

ANNUAL REPORT 2019/20

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Contents

1. Executive Summary

Significant progress has been achieved by SPAH in 2019/20 and the Steering Group took the opportunity at their meeting on 21 February 2020 to review progress over the three years of the last Service Agreement as well as to consider strategic priorities going forward. The strategic plan has been developed for inclusion in the Service Agreement for the network for 2020-23. A project undertaken during 2019/20 highlighted that Scotland serves increasing numbers of patients with Sickle cell disease from multiple geographical backgrounds. A higher proportion of adult patients with sickle cell disease have immigrated into Scotland from outwith the UK. In contrast, most of the paediatric patients have been born in the UK, with access to NHS healthcare since infancy. This has significance in planning for health care delivery to patients with sickle cell disease. In particular, it will have an impact as the increasing paediatric population transition into adult care services. Recognition of these findings will assist the network in facilitating appropriate service development for a consistent, multi-disciplinary team approach to clinical management of sickle cell disease in Scotland.

Education remains a priority for the network, with the aim to continue to build a range of resources for both professionals and other stakeholders. An Education Strategy has been developed for SPAH and endorsed at the Steering Group meeting on 30 August 2019. The network's approach to education responds to the findings of a Learning Needs Analysis, both in relation both in relation to the educational content and the most effective ways of structuring and delivering the education. During 2019/20 SPAH continued to provide a varied programme of education through:

- Multidisciplinary Meetings
- Laboratory Training Event
- Royal College of Emergency Medicine presentation
- Promoted link to the PHE module to Midwives.
- Development of Scottish Ambulance Service Bulletin
- Locally delivered education sessions

The network has a comprehensive timetable for review and development of guidelines and leaflets and facilitates this through the protocols and guideline sub-group which has met twice during the course of the year.

Collaborative working with Scottish Ambulance Service (SAS) has continued. A Hazard Alert has been developed which provides a brief summary of patient information and an immediate treatment plan. A bulletin has also been developed, which as the name suggests, is a one-page summary of key information on Sickle Cell Disease. To underpin this information, a small core group from the network visited the Ambulance Control Room to support them in gaining a better understanding of the questions that would be asked of families when calling for an ambulance and equip them with correct information to be developed into a patient information leaflet.

The adult Ferriscan Service received funding from National Services Division (NSD) to provide a bespoke service provided at the Queen Elizabeth University Hospital for individuals referred on a cost per case basis. A pathway has been developed and implemented for this service and will be reviewed in 2020/21.

Measuring performance has once again been a major objective for the network during 2019/20. Issues with Business Objects reporting through the Clinical Audit System (CAS) as well as other constraints resulted in data being unavailable for the best part of the year. These issues, although now resolved, resulted in delays in providing data to measure against the 6 Key Performance Indicators (KPIs).

Since February 2020, understandably NHS Scotland priority has been to prepare for and deal with COVID-19 impact and this has seen clinical and other resource diverted from network activity. The network has undertaken an exercise to not only capture the impact of this unprecedented situation on the current reporting period but also to assess the likely impact on delivery of the 2020/2021workplan.

2. Introduction

The Scottish Paediatric & Adult Haemoglobinopathy Network (SPAH) was designated as a National Managed Clinical Network (NMCN) on 1 April 2011.

The network was established to ensure appropriate links to the National Antenatal and Newborn Screening Programme for Haemoglobinopathies which was implemented in October 2010. The nationally funded Transcranial Doppler and Ferriscan services for children with Sickle Cell and Thalassaemia are also fully integrated with the Network.

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.

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.

- Sickle Cell Disease (Hb-SS, HBSC, HBS/Beta thalassaemia and other sickling disorders)

  Sickle cell disease is a lifelong inherited blood disorder primarily arising in people of African-Caribbean origin and less frequently in those from India, Pakistan, Southern Europe and the Middle East. It is characterised by a chronic anaemia, an increased susceptibility to infection and a propensity to acute vaso-occlusive crisis which can be painful and can cause widespread organ damage. Acute episodes can be life threatening and require prompt expert attention. Recurrent episodes result in chronic ill health affecting almost every organ. The morbidity associated with this organ damage can be lessened with appropriate clinical assessment and expert management.

- Beta Thalassaemia Major

  Beta thalassaemia predominantly affects people of Asian and Southern Mediterranean origin and results in a lifelong requirement for regular red cell transfusion every few weeks. The major health issues associated with thalassaemia relate to transfusional iron overload and organ damage.

The network has a remit to ensure that equitable, high quality care is delivered promptly to patients with haemoglobinopathies (Sickle Cell and Thalassaemia) 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.

3. Report on Progress against Network Objectives in 2019/20

National networks have agreed core objectives that reflect the Scottish Government's expectations for managed clinical networks, as described in CEL (2012) 29[1]. The network's core objectives are:

- Design and ongoing development of an effective Network structure that is organised, resourced and governed to meet requirements in relation to Scottish Government Health & Social Care Directorate (SGHSCD) Guidance on MCNs (currently CEL (2012) 29) (Annex) and national commissioning performance management and reporting arrangements;

- Support the development, design and delivery of services that are evidence based and aligned with current strategic and local and regional NHS planning and service priorities.

- Effective Stakeholder Communication and Engagement through design and delivery of a written strategy that ensures stakeholders from Health, Social Care, Education, the Third Sector and Service Users are involved in the Network and explicitly in the design and delivery of service models and improvements.

- Improved capability and capacity in haemoglobinopathy care through design and delivery of a written education strategy that reflects and meets stakeholder needs.

- Effective systems and processes to facilitate and provide evidence of continuous improvement in the quality of care (CQI).

- Generate better value for money in how services are delivered.

This report gives an overview of progress against these objectives in the year 2019/20.

3.1. Effective Network Structure and Governance

Through the management structure and terms of reference for the network Steering Group and sub-groups, SPAH meets the core principles of managed clinical Networks as set out in CEL (2012) 29. Workplans and reports are published on the network website, and any documents produced by the network are publically available for clinicians and patients to view.

Dr Susan Baird was appointed to the role of Lead Clinician for the network from June 2017 to June 2020. Following agreement by the SPAH Steering Group and NSD Senior Management Team Dr Baird's appointment will be extended for a year until June 2021.

The network is supported through the National Network Management Service (NNMS) in NHS NSS by a Programme Manager, Mhairi Gallacher, a Programme Support Officer, Laura Craig and Data Analyst, Gavin Hallford.

The SPAH Steering Group took the opportunity at their Steering Group meeting on 21 February 2020 to review progress over the three years of the last Service Agreement in place 2017-2020 as well as to consider strategic priorities for the next three years 2020-23. The strategic plan has been developed for inclusion in the Service Agreement for the network for 2020-23.

Steering Group meetings are chaired by the Lead Clinician and members have a responsibility to communicate effectively between the MCN, relevant professions and their respective organisations. The Steering Group met on three occasions during 2019/20 and the list of members is included in **Appendix 1**.

The SPAH Steering Group endorsed the terms of reference at the meeting on 30 August 2019.

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[1] Please see: https://www.sehd.scot.nhs.uk/mels/CEL2012_29.pdf

3.2. Service Development and Delivery

Guidelines & Pathways

The network has a timetable for the review and development of clinical guidelines and pathways. There are currently a total of 27 guidelines available to staff involved in providing care for patients with haemoglobinopathies and 6 pathways. During 2019/20, 8 of the 27 guidelines were due for review and 6 have been completed and available on the website. The remainder are nearing completion. Of the 6 pathways, four were due for review in 2019/20, with 3 completed and one nearing completion.

Ten new guidelines have been proposed for development and in this reporting period, two have been completed. Progress is underway for the development of the other eight.

Guidelines and pathways are available from the SPAH website - http://www.spah.scot.nhs.uk/professionals/

Patient/Family Information Leaflets

During 2019/20 the Nursing Sub-Group were focussing on reviewing and updating the network's patient and family leaflets. This objective was prioritised following feedback during a workshop at the Patient/Family event which provided consensus for the re-formatting of all patient information leaflets into one uniformed approach. The network has liaised with the Communication Department to produce a template and the project is well underway to review and update all network leaflets.

3.3. Stakeholder Communication and Engagement

Website

The website has been regularly updated and is a valuable source of information for patients and professionals alike. SPAH has worked with a designer to create new branding which will be implemented during 2020/21. Website analytics is available in **Appendix 2** which shows a significant upward trend with doubling of visits to the website.

Newsletter

The network issued a newsletter in June via email to SPAH stakeholders and also uploaded to the website. The newsletter included updates from the sub groups, progress on quality improvement projects and an update and photos from the Rare Disease Day in the Scottish Parliament where Dr Baird was given the opportunity to promote the ongoing work of SPAH.

Transition

The network is using QI methodology to review and improve the transition process for patients. The collection of retrospective baseline data has been ongoing since early 2018, and it was acknowledged this project would take a number of years to collect quantitative and qualitative data as the number of patients transitioning in any one year is small. Data will then be collected prospectively on those going through the process following the Ready Steady Go Hello programme. This programme helps young people gain the knowledge and skills to manage their condition by preparing them for moving to adult services.

3.4. Education

During 2019-20 one of the network's key priorities is the development of its Education Strategy which includes delivery of education sessions to the wider haematology community in Scotland. The Education Strategy has three key themes:

1. Education aimed at health professionals in secondary care with a specific remit for haemoglobinopathies
2. Education aimed at health professionals in secondary care without a specific remit for SPAH, such as midwives, A&E staff, Scottish Ambulance Service
3. Professionals without direct involvement in SPAH

The levels of education to be delivered to each of these have been identified and are as follows:

1. Delivery of education events, multidisciplinary meetings and newsletters
2. Promoting educational resources available from other sources e.g. Public Health England (PHE) and development of resources for SAS
3. Support from Specialist and other nurses, signposting to resources such as PHE and SPAH website

Multidisciplinary Meetings

In this reporting period, two multidisciplinary meetings took place in Glasgow with video links to four sites nationally. In addition to case presentations with learning points, specialist peer support was provided in individual cases of ongoing treatment of patients. Eight cases were discussed at these meetings.

Laboratory Event

To strengthen the delivery of education to the wider community a Laboratory Education Event was hosted on 12 November 2019 in the Teaching & Learning Centre, Queen Elizabeth University Hospital, Glasgow campus. The event was principally for laboratory staff but was open to interested clinicians and a total of 35 people attended the event. The programme included speakers from National External Quality Assessment Services (NEQAS) and experts from the fields of Mass Spectrometry and Oxford and Newborn Screening Laboratories. Twenty-three participants provided their evaluation of the event with 73% confirming the relevance of the event to their educational needs was highly relevant. The feedback to the overall quality of education provided was 78% excellent and 22% very good.

School Engagement

A questionnaire has been developed to establish if the school's information booklet, first developed in 2015, remains fit for purpose in providing adequate information for teachers who have a child(ren) in their school with Sickle Cell Disease and whether a leaflet to complement the booklet is required. The questionnaire was issued to schools via nursing staff however due to changes in nursing capacity the number returned was low. A total number of three questionnaires have been returned with all confirming no amendments required. Based on that, the network has chosen to sign off the booklet, with the review to be carried out in two years as opposed to the standard three years.

3.5. Audit and Continuous Quality Improvement

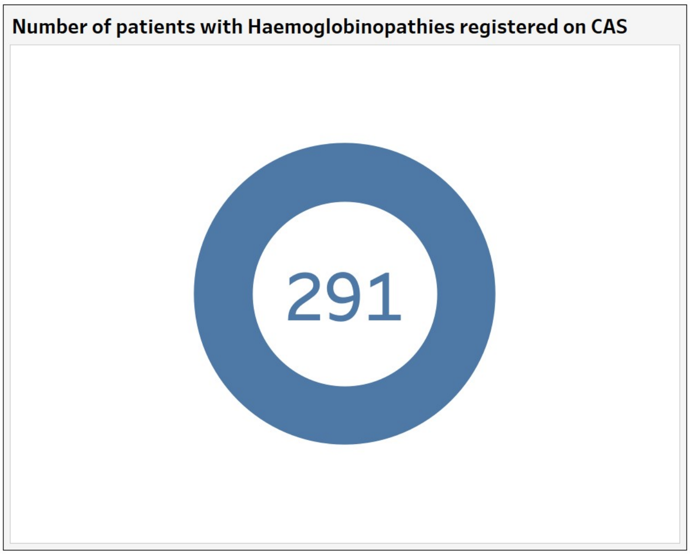
Transition Quality Improvement Project

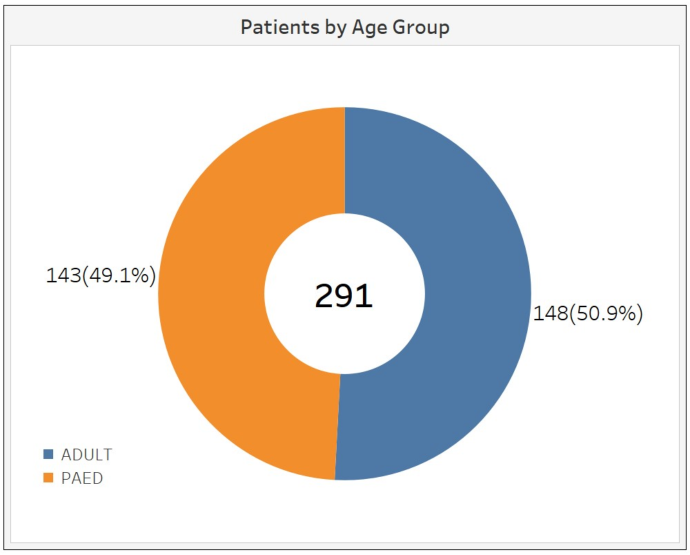
The network has been undertaking a project using QI methodology to improve the transition process. The first stage was to gather retrospective data on patients who have gone through the transition process. A baseline will be established and data collected prospectively on those going through the process following the implementation of the Ready Steady Go Hello programme. A questionnaire to capture this data has been circulated to paediatric and adult colleagues. Given the small number of patients the Network acknowledges that it may take 1-2 years to fully test and implement improvement ideas in this project.

Scottish Ambulance Service (SAS)

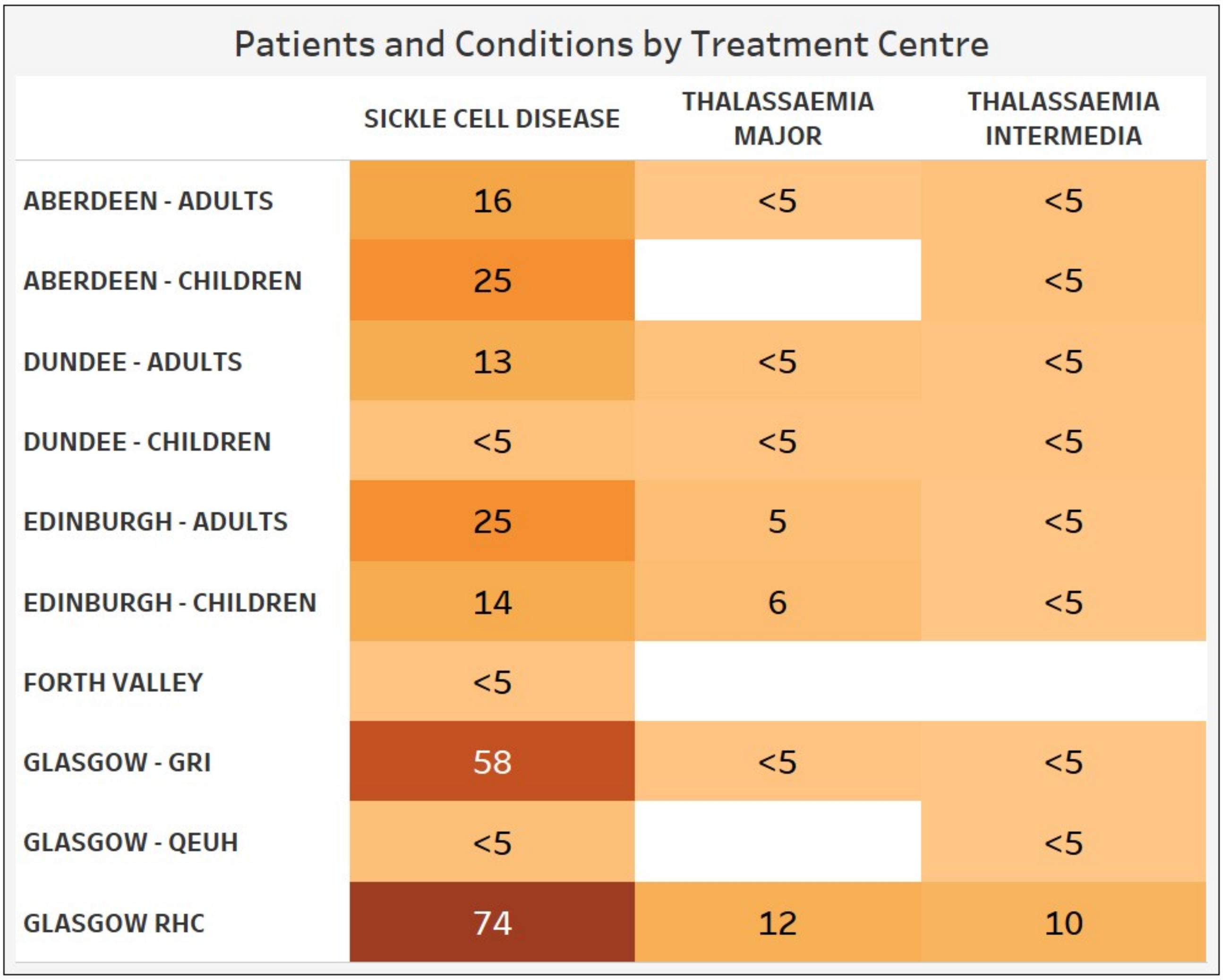
Collaborative working with Scottish Ambulance Service (SAS) is continuing apace. A Hazard Alert has been developed which provides a brief summary of patient information and an immediate treatment plan. The alert is then flagged on the SAS system to highlight the potential urgent nature of the patient's presentation. The Hazard Alert will only be available if a patient gives consent to their GP to upload it to the Key Information Summary. A bulletin has also been developed, which as the name suggests, is a one-page summary of key information on Sickle Cell Disease. To underpin this information, a small core group from the network visited the Ambulance Control Room to support them in gaining a better understanding of the questions that would be asked of families when calling for an ambulance and equip them with correct information to be developed into a patient information leaflet.

Patients with Haemoglobinopathies Registered on the National Clinical Audit System
The Clinical Audit System (CAS) continues to be the national register for SPAH. There are a total of **291** active follow-up patients currently registered on CAS an increase of 62 patients from 2018/19.

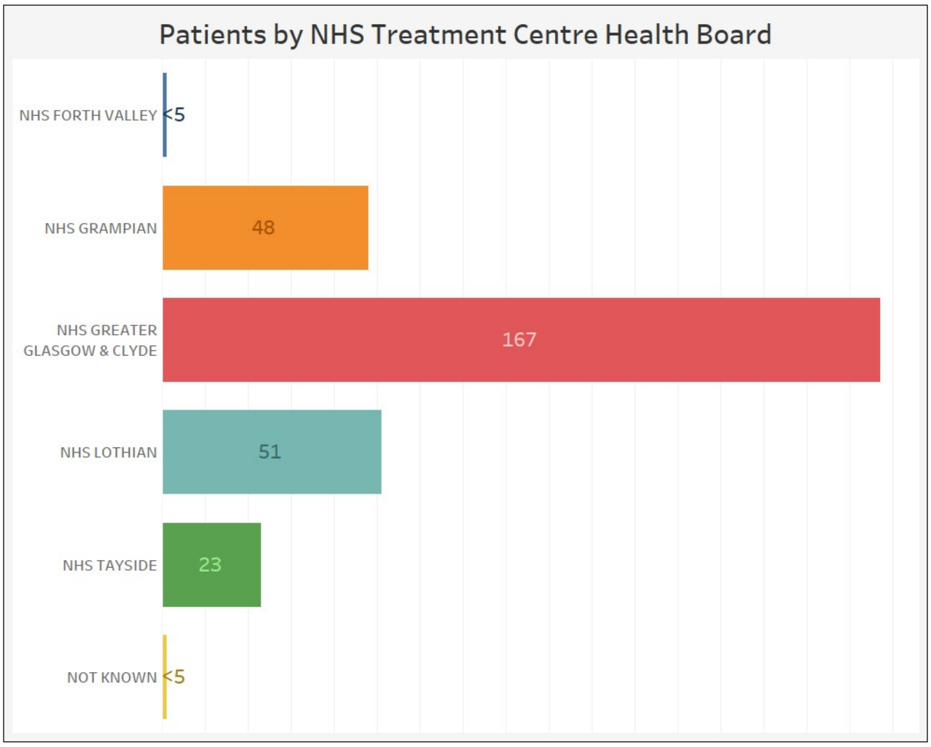

Number of patients with Haemoglobinopathies registered on CAS

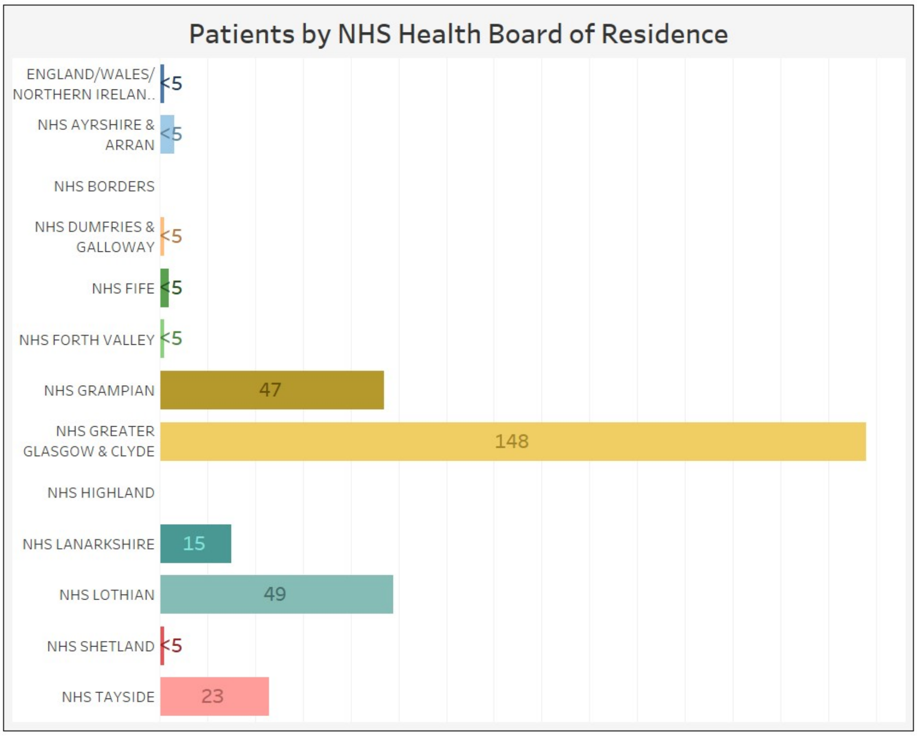

Patients by Age Group

The largest group is patients with Sickle Cell Disease, with the distribution across Scotland shown in the table below.


Patients and Conditions by Treatment Centre

	SICKLE CELL DISEASE	THALASSAEMIA MAJOR	THALASSAEMIA INTERMEDIA
ABERDEEN - ADULTS	16	<5	<5
ABERDEEN - CHILDREN	25		<5
DUNDEE - ADULTS	13	<5	<5
DUNDEE - CHILDREN	<5	<5	<5
EDINBURGH - ADULTS	25	5	<5
EDINBURGH - CHILDREN	14	6	<5
FORTH VALLEY	<5		
GLASGOW - GRI	58	<5	<5
GLASGOW - QEUH	<5		<5
GLASGOW RHC	74	12	10

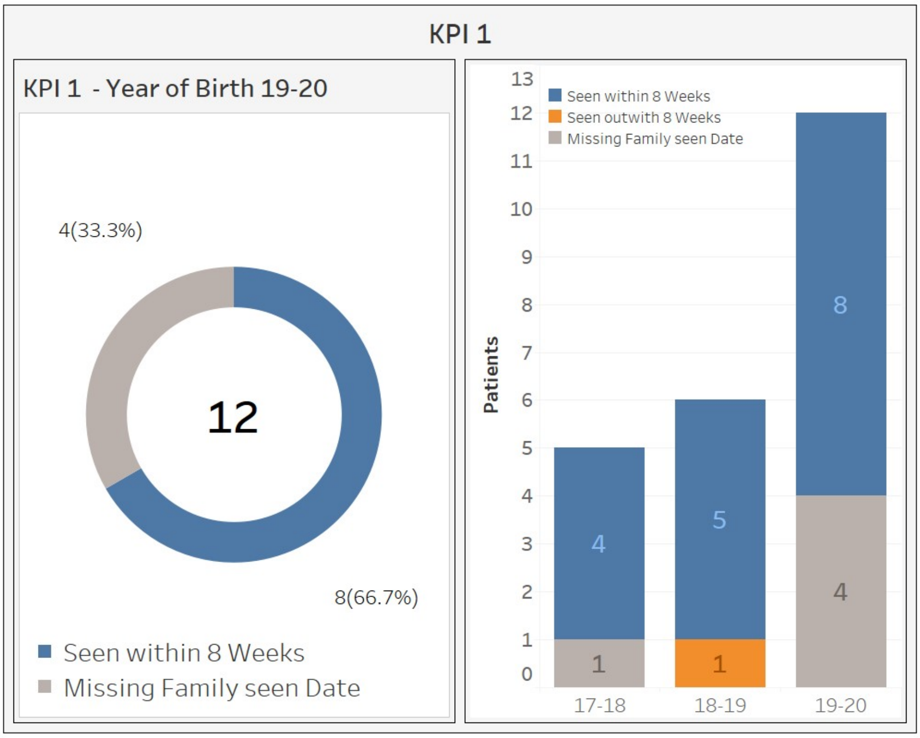




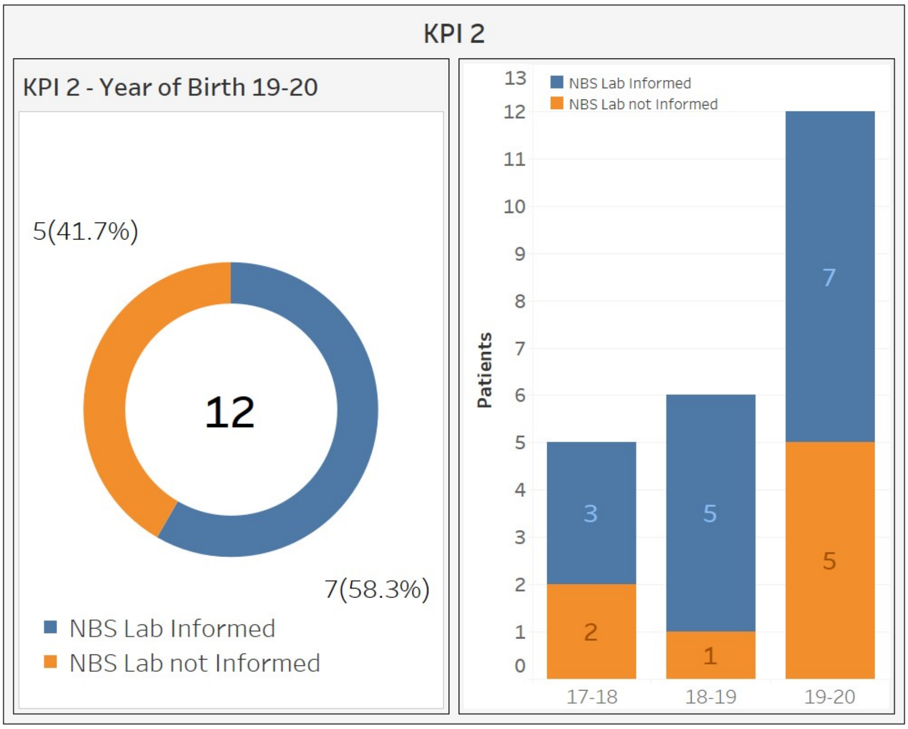
Reporting Against SPAH Key Performance Indicators

Measuring performance has once again been a major objective for the network during 2019/20. Issues with Business Objects reporting through the Clinical Audit System (CAS) as well as other constraints resulted in data being unavailable for the best part of the year. These issues, although now resolved, resulted in delays in providing data to measure against the 6 Key Performance Indicators (KPIs). ***The COVID-19 crisis has resulted in limitations on the necessary analysis of KPI results which will be prioritised and facilitated through the Data and Audit Sub-Group who will meet in September 2020. 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.

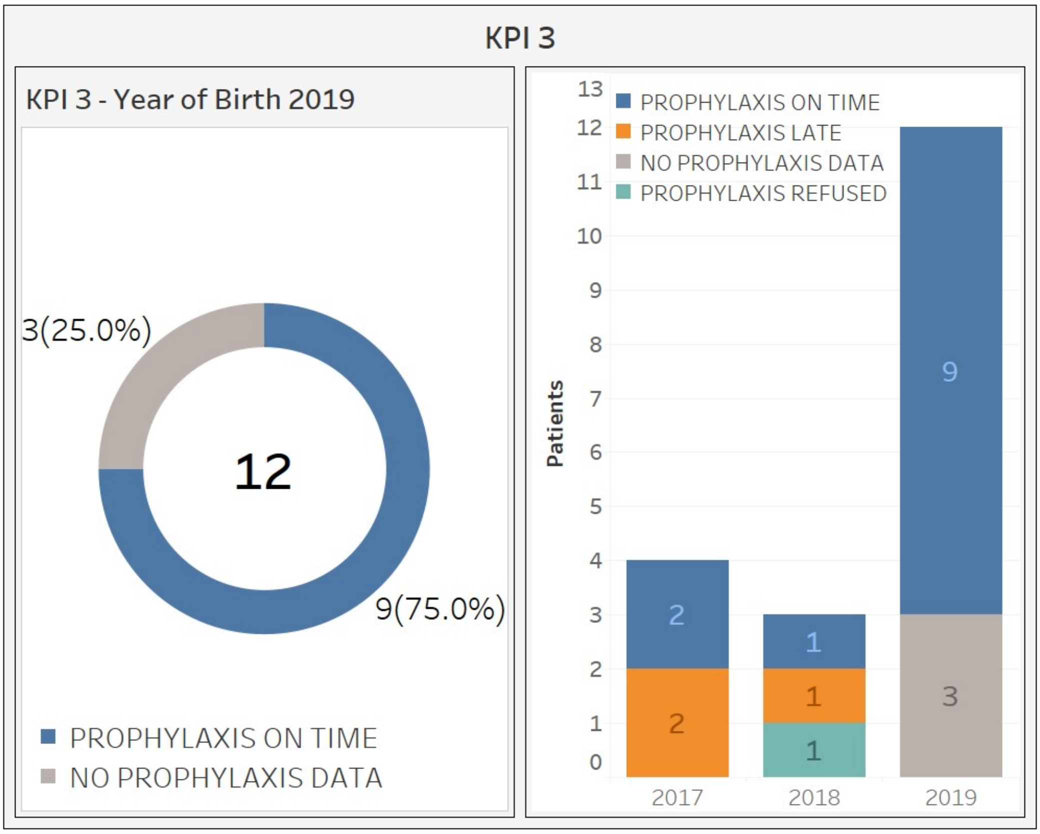


KPI 2 – 100% of screen positive babies in whom results of confirmatory testing are returned to the New Born Screening Laboratory.

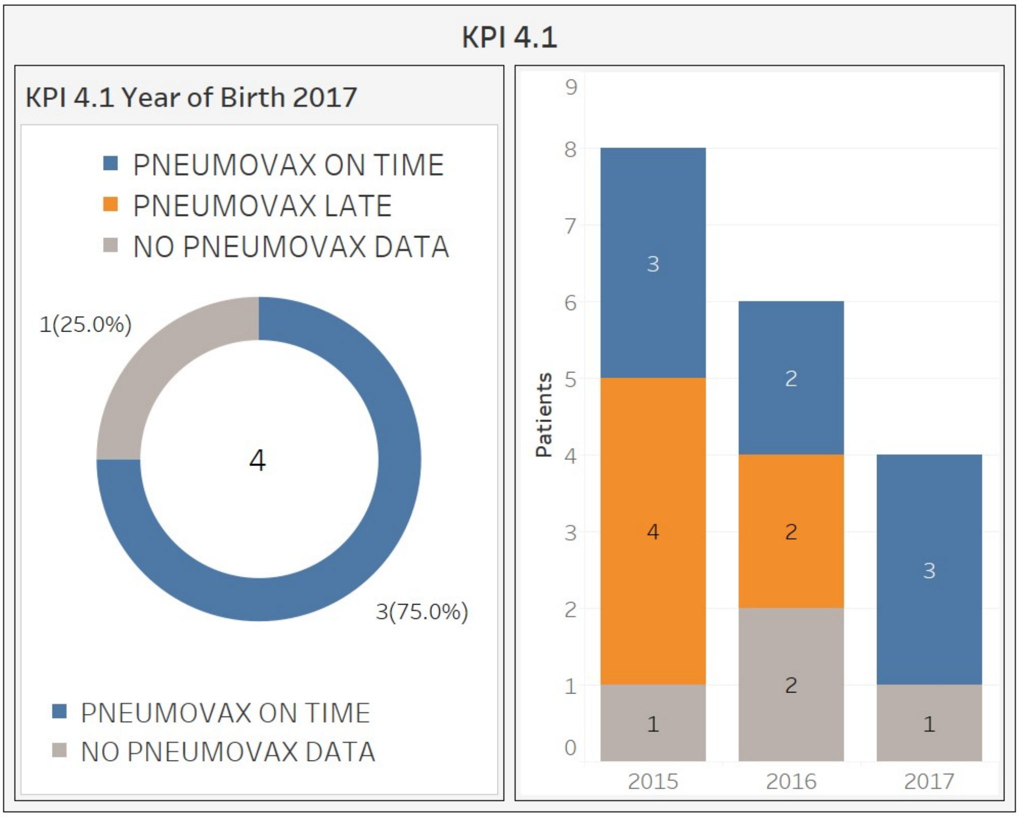


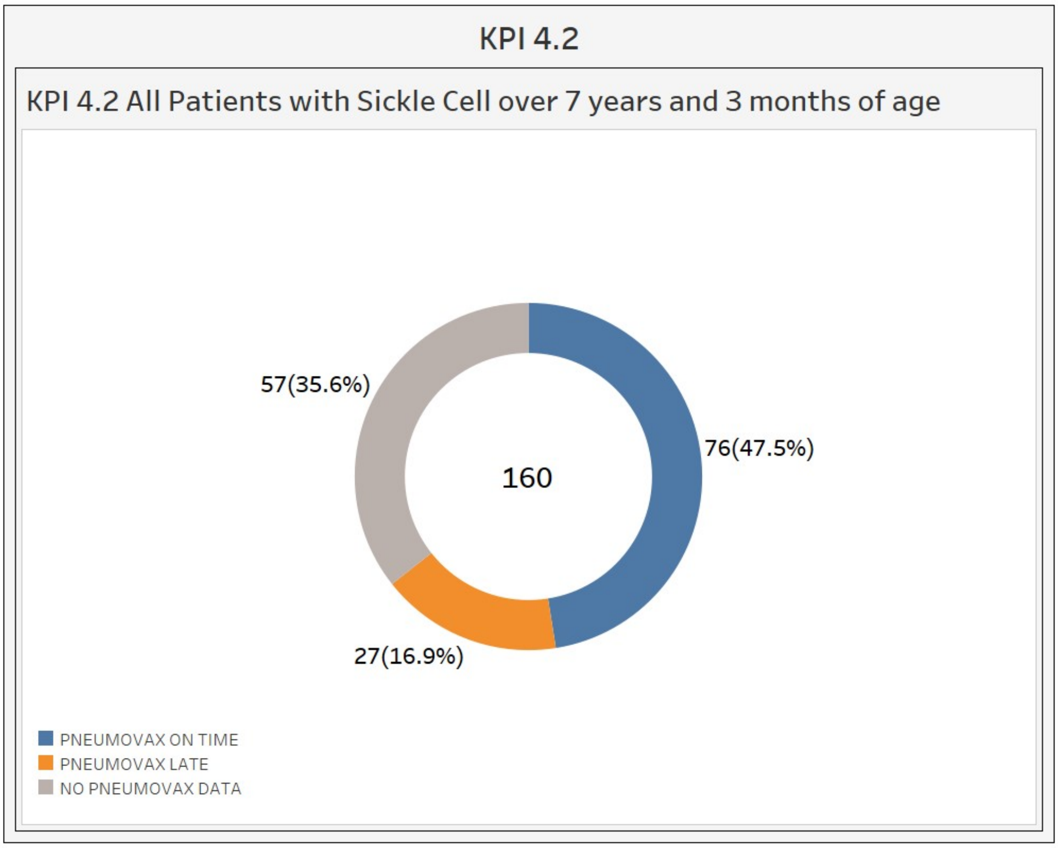
The network notes the doubling in the number of babies identified through new born screening during 19/20 and will explore if this continues in future years. The network will also review the process for capturing data for KP1 and KPI2 with New Born Screening.

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

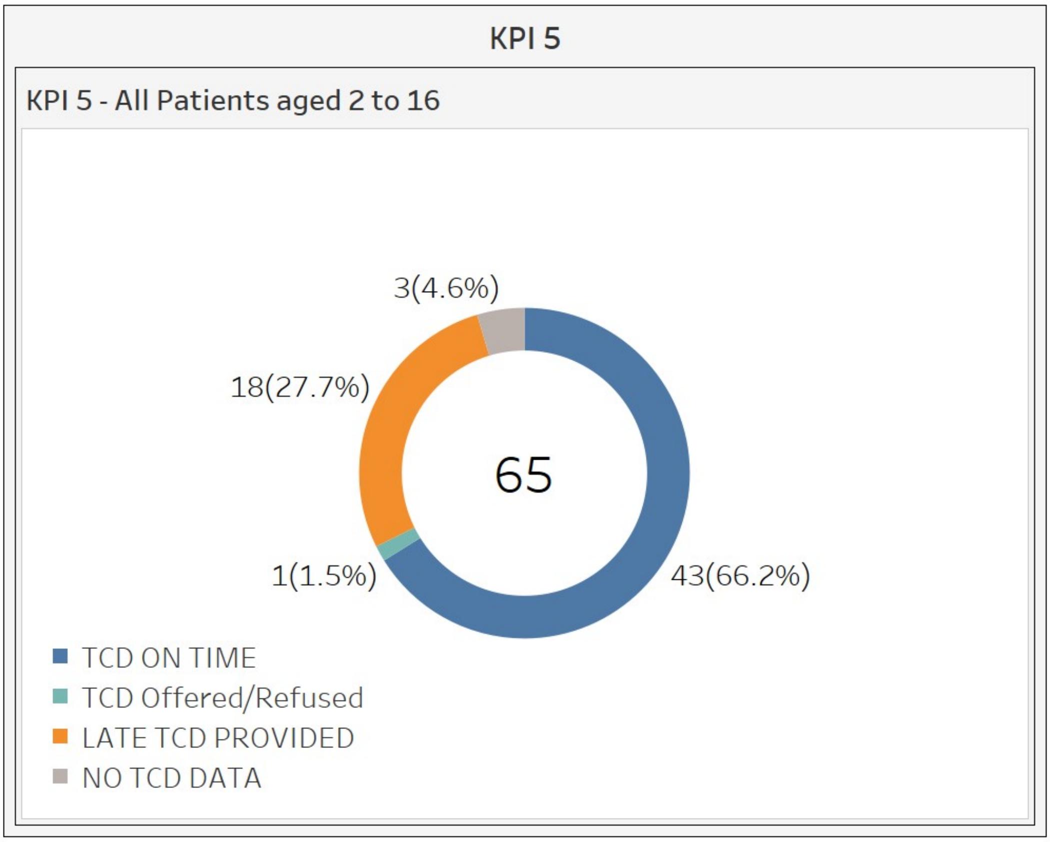


KPI 4 – 95% of patients should be given first Pneumovax (polycaccharide antigen) by 27 months and 5 yearly thereafter.

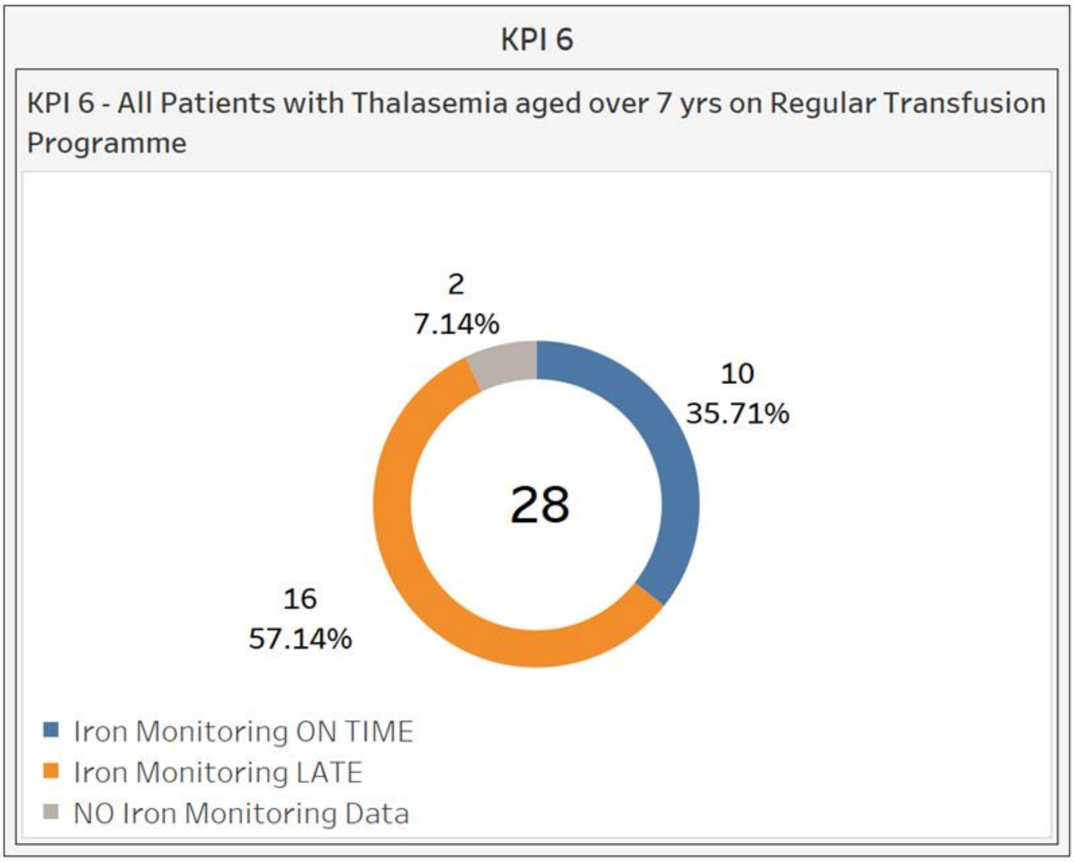




KPI 5 – 100% of children with HbSS or HbS/Beta thalassemia aged 2-16 years offered an annual TCD scan.



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.



Due to issues with data processing the new KPI “100% of patients with Thalasssaemia or Sickle Cell disease should be offered an annual review” has been postponed for collection during 2020/21 however this may be further delayed due to changes in practice in light of COVID-19 crisis.

Quarterly update reports will be issued to clinicians during 2020/21 to improve data capture as well as assisting clinicians with identifying patients due inoculations and scans. The audit sub-group will also investigate reasons for late scans to identify areas for improvement.

3.6. Value

During 2019/20 SPAH provided added value to NHS Scotland services, clinicians and patients and their families by:

- Facilitating consistent evidence-based practice throughout Scotland through the development of clinical guidance on the management of patients with haemoglobinopathies, which improves equity of access to high quality care and reduces harm arising from unwarranted variation.
- Developing and auditing relevant KPIs that enable clinical services to assess the quality of care they provide and identify continuous improvements.
- Providing effective communication channels via the network website, newsletters and widening stakeholder involvement, that give all relevant clinicians and patients and their families the opportunity to inform the work of the network and relevant NHS services.
- Collaborating with other networks, such as the Scottish Clinical Imaging network, to avoid duplication of work and wasted resources.

4. Plans for the Year Ahead

Key priorities:

- Organise and host a SpR Education Day in Summer 2020
- Organise and host a Families Event in Spring 2021
- Continue to develop and review clinical protocols, guidelines and information leaflets, for both professional and patient groups
- Undertake reporting against 7 Key Quality Indicators
- Implement new design of the SPAH website. Maintain and review the content of the website to ensure it is accurate and up to date.
- Complete Quality Improvement Project collaboration between Scottish Ambulance Service and SPAH.
- Review of services including genetics, regional adult services and haemoglobinopathy laboratory services

Risks/Issues:

Adult Ferriscan Service - It is a key national recommendation and has been practice to assess cardiac and liver iron overload at least annually in chronically transfused paediatric and adult sickle cell and thalassemia patients by liver ferriscan and cardiac MRI. The Ferriscan service previously provided to all adult patients in Scotland at two locations (Grampian and Forth Valley) is no longer available.

Due to the unavailability of Ferriscan there is a risk that iron overload cannot be optimally assessed in line with National Guidance. This may impact clinicians ability to optimise the treatment of iron overload to avoid long term complications for patients.

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. The network is working with the Scottish Clinical Imagine Network (SCIN) to explore the feasibility of scans being provided locally in the NHS.

5. Detailed Description of Progress in 2019/20

Key

RAGB status	Description
RED (R)	The network is unlikely to achieve the objective by the agreed end date.
AMBER (A)	There is a risk that the network will not achieve the objective by the agreed end date but progress has been made.
GREEN (G)	The network is on track to achieve the objective by the agreed end date.
BLUE (B)	The network has been successful in achieving the network objective to plan.

Objective Number	Smart Objective	Planned start/ end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at31/03/2020	Anticipated Outcome	RAGB status
1. Effective Network Structure and Governance [linked to Quality Dimensions 3,4,5,6]						
2019-01	Organise 3 Steering Group meetings to ensure effective delivery of the 2019/20 workplan	April 2019/ March 2020	Steering Group	Steering Group Meetings: 30 August 2019 29 November 2019 21 February 2020	Effective delivery of the SPAH network work plan to ensure continuation of progress.	**B**
2019-02	The network will have Terms of Reference in place for the work of the Steering Group.	30 August 2019	Steering Group	Endorsed at Steering Group Meeting on 30 August.	There are effective governance arrangements in place.	**B**
2019-03	The network will meet reporting requirements: - Mid-year Report - Annual Report	31/10/19 31/05/20	Lead Clinician/ Programme Manager	Mid-Year Report available Annual Report available	There are effective governance arrangements in place.	**B**
2. Service Development and Delivery [linked to Quality Dimensions 1,2,3,4,5,6]						
2019-04	Review 5 existing and develop 6 new clinical guidelines relevant to adult haemoglobinopathy services	April 2019 / March 2020	Adult Protocol/ Guideline sub group	Review of 5 Existing Adult Guidelines: 4 COMPLETED: • 2 x Physiotherapy • Thalassaemia outpatient • Sickle Cell outpatient	A suite of evidence based adult guidelines will ensure high quality haemoglobinopathy care throughout Scotland.	**G**

Objective Number	Smart Objective	Planned start/ end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at31/03/2020	Anticipated Outcome	RAGB status
				1 OUTSTANDING: • Hyperhaemolysis (almost finalised). <u>Develop 6 new guidelines:</u> 1 COMPLETED: • Iron Chelation 5 OUTSTANDING: • Acute Anaemia • Thalassaemia Endocrine • Leg Ulcers • Surgery • Renal (These guidelines are nearing completion).		
2019-05	Review 3 existing and develop 3 new clinical guidelines relevant to paediatric haemoglobinopathy services	April 2019 / March 2020	Paediatric Protocol/ Guideline sub group	<u>Review of 3 existing Paediatric Guidelines:</u> 2 COMPLETED: • Acute Chest Syndrome • Surgery & Anaesthesia 1 OUTSTANDING: Sickle Cell-Chronic Transfusion <u>Development of 3 new guidelines:</u> • TCD referral guideline • Thalassaemia Intermedia • Transfer of acutely unwell paediatric patients for Specialist Management Three new guidelines drafted		**G**
2019-06	Review 3 existing and develop 1 new clinical pathway	July 2019 / March 2020	Joint Paediatric & Adult Protocol/ Guideline sub group	<u>Review of 4 existing Clinical Pathways:</u> 3 COMPLETED • Adult Ferriscan referral • New case identified by Newborn Screening		**G**

Objective Number	Smart Objective	Planned start/ end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at31/03/2020	Anticipated Outcome	RAGB status
				• Diagnosed beyond Newborn Screening Development of 1 new Pathway: • Transplant referral		🟩
2019-07	Review 6 paediatric patient information leaflets, 4 adult patient information leaflets, and develop 5 new patient information leaflets.	April 2019 / March 2020	Nurses sub group	Review of 6 existing Paediatric Information leaflets: 4 COMPLETED: • TCD – outwith GG&C • Antibiotics • Hydroxycarbamide (young person) • Travel 2 OUTSTANDING: • Priapism (parent) • Vaccination Review of 4 existing adult information leaflets: 3 COMPLETED: • Antibiotics • Hydroxycarbamide • Travel 1 OUTSTANDING: • Priapism Development of 5 new information leaflets: 1 COMPLETED: • Sickle Cell disease information for GPs (adult) 4 OUTSTANDING: • Thalassaemia Major (parent) • Acute Chest Syndrome (adult) • Acute Chest Syndrome (paed) • Transition	Patients and their families/carers have access to good quality, up to date information to support them in living with their condition.	G

Objective Number	Smart Objective	Planned start/ end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at31/03/2020	Anticipated Outcome	RAGB status
2019-08	Scope provision of adult Ferriscan across Scotland in collaboration with Scottish Clinical Imaging Network (SCIN) and Scottish Medical Physics MRI group.	April 2019 / March 2020	Susan Baird	Discussion ongoing with, SCIN Network. Short term pathway finalised for Ferriscan provision at RHC on cost per case basis.	An equitable service provision for adult patients across Scotland	G
3. Stakeholder Communication and Engagement [linked to Quality Dimensions 1,3,4,5,6]						
2019-09	Develop a questionnaire to establish if the Schools booklet provides adequate information for *teachers and whether a leaflet to complement the booklet is required.*	June 2019/ December 2019	Mhairi Gallacher	Questionnaire developed and distributed by Nurses when visiting schools. Small number of questionnaires completed. Feedback confirmed booklet provides adequate information.	Collaboration with Education organisation to develop stronger links	B
2019-10	Review and maintain the SPAH website to ensure it is accurate and up to date.	April 2019 / March 2020	Laura Craig	Website updated regularly. New website designs will be implemented during in 2020/21.	Improved engagement with both professionals and patients	B
2019-11	Conduct a learning needs analysis (LNA) with the following professional groups to inform development of Network's education strategy. • Accident & Emergency departments • Consultants in Haematology	April 2019 / March 2020	Susan Baird/ Laura Craig/ Mhairi Gallacher	LNA undertaken (only 10 fully completed) and feedback used to develop education strategy for the network.	Professionals in Scotland will be up-skilled in their knowledge of haemoglobinopathies	B
2019-12	Raise awareness of work of SPAH network through co-hosting stall with Sickle Cell Society at British Society of haematologist conference.	April 2019	Laura Craig/ Mhairi Gallacher	Event attended on 2 April 2019.	Clinicians in Scotland are aware of work of SPAH.	B
4. Education [linked to Quality Dimensions 1,2,3,4,5,6]						
2019-13	Develop and endorse education strategy.	30 August 2019	Mhairi Gallacher	Endorsed at Steering Group meeting on 30 August.		B

Objective Number	Smart Objective	Planned start/ end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at31/03/2020	Anticipated Outcome	RAGB status
2019-14	Organise and host a Laboratory Education event working with Biomedical Scientist to develop a programme.	April 2019/ October 2019	Laura Craig/ Patricia Ryan	Event held on 12th November 2019. Well attended and evaluated	Increased knowledge in haemoglobinopathies for relevant healthcare professionals	B
2019-15	Organise, host and evaluate a minimum of 2 Multidisciplinary meetings that facilitates professionals from Scotland and Ireland to engage.	April 2019 / March 2020	Laura Craig	MDT meetings scheduled for: 13 September 2019 25 March 2020	Improved knowledge in haemoglobinopathies for healthcare professionals that either reinforces existing best practice or results in changes in practice	B
2019-16	By March 2020 organise and host an education event aimed at Specialist Registrars/Trainees	June 2019/ March 2020	Mhairi Gallacher/ Laura Craig	Due to staff commitments this will now be arranged for Autumn 2020.	Increased knowledge in haemoglobinopathies for relevant healthcare professionals	A
2019-17	Deliver education to Royal College of Emergency Medicine in line with results from LNA (as per 2019-11)	June 2019/ March 2020	Susan Baird	Dr McIlwaine delivered presentation to around 150 delegates at RCEM meeting on 14 May 2019.	Increased awareness and knowledge of conditions in professionals not routinely involved in management	B
2019-18	Promote link to the PHE module to Midwives.	April 2019/ March 2010	Susan Baird/ Mhairi Gallacher	27 July - Link issued to Chair of the National Head of Midwifery to disseminate on network's behalf.		B
5. Audit and Continuous Quality Improvement [linked to Quality Dimensions 1,2,3,4,5,6]						
2019-19	Data collection on new KPI - "Annual review"	April 2019/ March 2020	IT/Audit sub group	Due to issues with obtaining data from CAS data collection for this KPI will commence on 1 April 2020.	Improvements to service delivery are progressed from audit.	A
2019-20	Develop a Quality Strategy to outline the network's approach for improving quality in haemoglobinopathy services.	May 2019/ November 2019	Mhairi Gallacher	Quality Strategy endorsed at Steering Group Meeting on 30 August 2019.	Clinicians will work together to drive improvements for patient care	B
2019-21	Continue delivery of a programme of audit against Key Performance Indicators	April 2019 / March 2020	IT/Audit sub group	Delays experienced in collating data from CAS.	Improvements to service delivery are progressed from audit.	A

Objective Number	Smart Objective	Planned start/ end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at31/03/2020	Anticipated Outcome	RAGB status
2018-08	Continue collation of data in relation to transition including feedback on the implementation of Ready Steady Go Hello programme to capture improvement.	Ongoing	Susan Baird/ Laura Craig/ Mhairi Gallacher	Data collated from a small number of patients who transition each year.	Service improvements progressed.	A
2019-22	Continue Quality Improvement Project collaboration between the Scottish Ambulance Service and SPAH regarding implementation of online education and information materials.	April 2019 / March 2020	Susan Baird/ Laura Craig/ Mhairi Gallacher	Project ongoing: • Bulletin available on SAS intranet • Paragraph for patients' KIS to be written and then sent together with a letter to individual GPs to request uploading to patient file. Issuing letter delayed due to COVID-19 situation. • Slot requested at the Lead Clinician Dev Day to discuss SAS. Possibly looking at recording 1min videos with other Lead Clinicians of networks working with SAS (SPEN, SOCN, SPEG). • SAS to provide posters which can be placed in Nurses areas.	Patients will benefit from organisations working together to provide optimum care and manage risk better	G
6. Value **[linked to Quality Dimensions 1,2,3,4,5,6]**						

6. Proposed Work Plan for 2020/21

Objective Number	Smart Objective	Planned start/ end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at xxxxxx	Anticipated Outcome	RAGB status
1. Effective Network Structure and Governance [linked to Quality Dimensions 3,4,5,6]						
2020-01	Organise 3 Steering Group meetings to ensure effective delivery of the 2020/21 workplan	April 2020/ March 2021	Steering Group	Steering Group Meetings: 12 June 2020 Two additional dates to be organised	Effective delivery of the SPAH network work plan to ensure continuation of progress.	
2020-02	The network will meet reporting requirements: - Mid-year Report - Annual Report	31/10/20 31/05/21	Lead Clinician/ Programme Manager		There are effective governance arrangements in place.	
2. Service Development and Delivery [linked to Quality Dimensions 1,2,3,4,5,6]						
2020-03	Review 9 existing and develop 5 new clinical guidelines or pathways relevant to adult haemoglobinopathy services. NEW Guidelines • Acute Anaemia • Thalassaemia Endocrine • Leg Ulcers • Surgery • Renal	April 2020 / March 2021	Adult Protocol/ Guideline sub group		A suite of evidence based adult guidelines will ensure high quality haemoglobinopathy care throughout Scotland.	
2020-04	Review 5 existing and develop 4 new clinical guidelines and pathways relevant to paediatric haemoglobinopathy services NEW Guidelines • TCD referral • Thalassaemia Intermedia	April 2020 / March 2021	Paediatric Protocol/ Guideline sub group			

Objective Number	Smart Objective	Planned start/ end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at xxxxxx	Anticipated Outcome	RAGB status
	- Transfer of acutely unwell paediatric patients for Specialist Management NEW Pathway - Transplant					
2020-05	Review 3 paediatric patient information leaflets, 1 adult patient information leaflet, and develop 9 new patients information leaflets	April 2020 / March 2021	Nurses sub group		Patients and their families/carers have access to good quality, up to date information to support them in living with their condition.	
2019-08	Scope provision of adult Ferriscan across Scotland in collaboration with Scottish Clinical Imaging Network (SCIN) and Scottish Medical Physics MRI group.	April 2019 / March 2020	Susan Baird	Discussion ongoing with, SCIN Network. Short term pathway finalised for Ferriscan provision at RHC on cost per case basis.	An equitable service provision for adult patients across Scotland	
2020-06	Review provision of Adult Ferriscan Services at Royal Hospital for Children, Glasgow.	April 2020/ March 2021	Mhairi Gallacher		Service is being utilised to ensure ongoing continuity	
2020-07	Work with HaTS Network to review and standardise lab haemoglobinopathy services across Scotland (including Genetic Services).	April 2020/ March 2021	Beverley Robertson/ Trish Ryan/ Susan Baird		An equitable service provision for patients across Scotland	
2020-08	Review Regional Adult Services.	April 2020/ March 2021	Louisa McIlwaine			
3. Stakeholder Communication and Engagement [linked to Quality Dimensions 1,3,4,5,6]						
2020-09	Implement new design of the SPAH website. Maintain and review the content of the website to ensure it is accurate and up to	May 2020 / March 2020	Laura Craig		Improved engagement with both professionals and patients	

Objective Number	Smart Objective	Planned start/ end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at xxxxxx	Anticipated Outcome	RAGB status
	date.					
2020-10	Produce two Newsletters (summer and winter) to share with colleagues in Scotland and available from the SPAH website	June 2020/ January 2021	Laura Craig		Increase awareness of SPAH activity	
2020-11	Organise and host a Family Event working with patients/carers to develop programme.	Spring 2021	Laura Craig		Increase engagement with patients and families and have a better understanding of their priorities to address in future	
2020-12	Develop more consistent communication pathways and linkage between antenatal screening, newborn screening and paediatrics.	April 2020/ March 2021	Beverley Robertson/ Susan Baird /Mhairi Gallacher			
4. Education **[linked to Quality Dimensions 1,2,3,4,5,6]**						
2020-13	Implement new format of organising, hosting and evaluating monthly Multidisciplinary meetings that facilitates professionals from Scotland and Ireland to engage.	April 2020 / March 2021	Laura Craig		Improved knowledge in haemoglobinopathies for healthcare professionals that either reinforces existing best practice or results in changes in practice	
2019-16	Organise and host an education event aimed at Specialist Registrars/Trainees	June 2020/ August 2020	Laura Craig/ Glasgow clinicians		Increased knowledge in haemoglobinopathies for relevant healthcare professionals	
2020-14	Promote link to the PHE module to Midwives.	June 2020/ July 2020	Laura Craig		Sharing of external education available to colleagues in Scotland	

Objective Number	Smart Objective	Planned start/ end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at xxxxxx	Anticipated Outcome	RAGB status
2020-15	Explore and progress membership of the West London HCC and National haemoglobinopathy advisory panel for specialist advice on management of sickle cell and thalassemia patients in Scotland.	April 2020/ March 2021	Susan Baird/Mhairi Gallacher		Collaborative and supportive working with colleagues in England	
2020-16	Deliver education at the Rare Diseases Event in Autumn 2020.	August 2020/ March 2021	Susan Baird		Raising profile of conditions and of the Network	
2020-17	Consider education requirements for haematologists.	April 2020/ March 2021	Susan Baird			
2020-18	Deliver education session to University of Glasgow Undergraduate Nurses on care of adults with Sickle Cell and Thalassaemia.	September 2020/ March 2021	Louisa McIlwaine		Building on student nurses education on haemoglobinopathies	
5. Audit and Continuous Quality Improvement [linked to Quality Dimensions 1,2,3,4,5,6]						
2019-19	Data collection on new KPI - “Annual review”	April 2020/ March 2021	IT/Audit sub group	Due to issues with obtaining data from CAS data collection for this KPI will commence on 1 April 2020.	Improvements to service delivery are progressed from audit.	
2020-19	Ensure CAS is reliably working to progress delivery of an audit programme against Key Performance Indicators	April 2020/ March 2021	Mhairi Gallacher/ Laura Craig/ IMS Team		Improvements to service delivery are progressed from audit.	
2020-20	Explore benchmarking opportunities against the rest of the UK through collaboration with National Haemoglobinopathy Register.	March 2021	IT/Audit sub group		Continuing programme of audit will ensure high quality haemoglobinopathy care throughout Scotland	

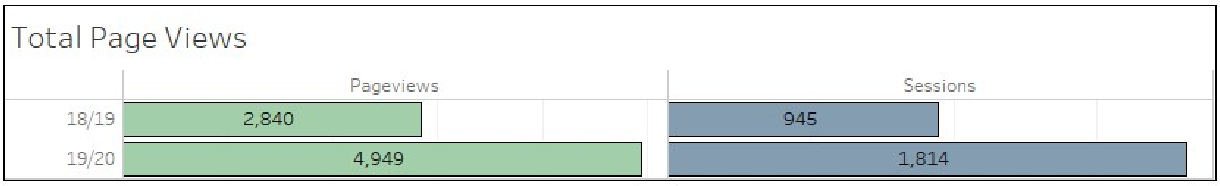
Objective Number	Smart Objective	Planned start/ end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at xxxxxx	Anticipated Outcome	RAGB status
2020-21	Execute a time to analgesia audit.	April 2020/ March 2021	IT/Audit sub group		Improvements to service delivery are progressed from audit.	
2020-22	Continue Quality Improvement Project collaboration between Scottish Ambulance Service and SPAH including: • Implementation of Key Information Summary (KIS), Hazard Alert notification form and covering letter to GPs • Consider working collaboratively with other networks who are working with SAS to develop a patient information leaflet. • Provide update at Lead Clinicians forum.	April 2020/21	Susan Baird/Mhairi Gallacher/ Laura Craig		Patients will benefit from organisations working together to provide optimum care and manage risk.	
2020-23	Review transition before and after the implementation of the Ready Steady Go programme to capture improvement.		Susan Baird/ Ruth Bissell Laura Craig/ Mhairi Gallacher		Service improvements progressed.	
6. Value **[linked to Quality Dimensions 1,2,3,4,5,6]**						

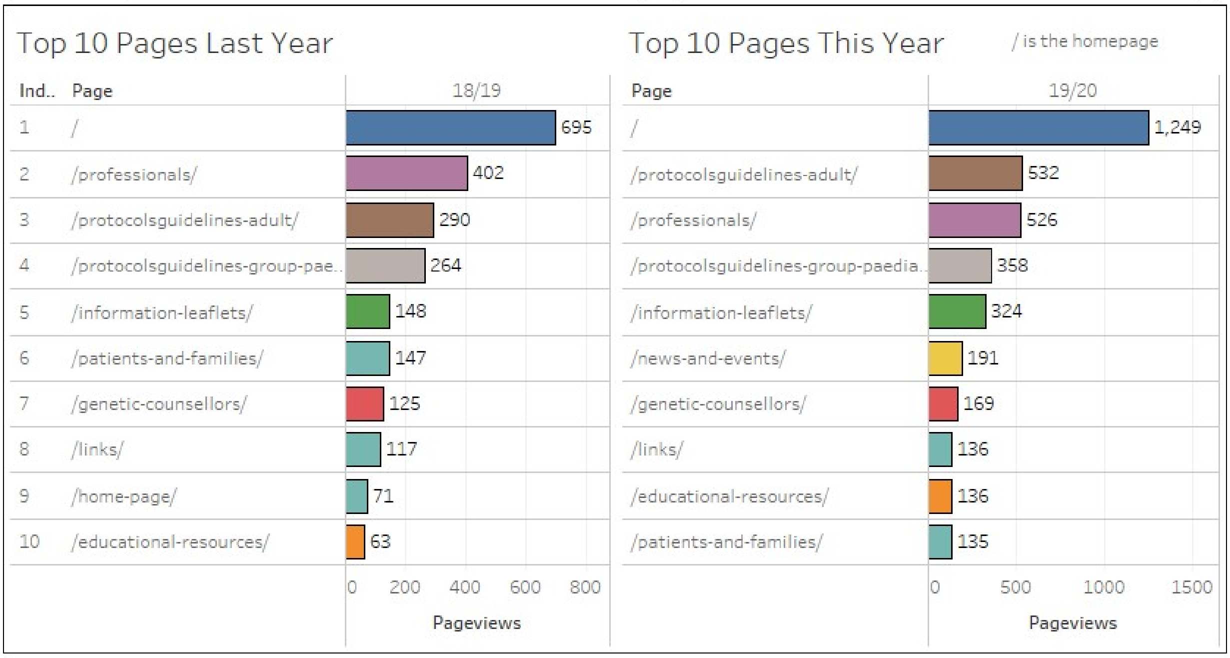
Appendix 1: Steering Group Membership

Ruth Allen	Consultant Paediatric Radiologist	NHS GG&C
Susan Baird	Consultant Paediatric Haematologist	NHS Lothian
Ruth Bissell	Haematology Nurse Specialist	NHS GG&C
Vicky Brace	Consultant Obstetrician	NHS GG&C
Elizabeth Chalmers	Consultant Paediatric Haematologist	NHS GG&C
Sarah Dack (deputising For Trish Ryan)	Haematology BMS Professional Manager	NHS Fife
Louise Forrest	Clinical Nurse Specialist	NHS Grampian
Buddhi Gunaratne	Consultant Paediatrician	NHS Tayside
Lyn Hutchison	Senior Programme Manager	NHS NSS
Angela Iley	Genetic Counsellor	NHS GG&C
Louisa McIlwaine	Consultant Haematologist	NHS GG&C
Beverley Robertson	Consultant Haematologist	NHS Grampian
Trish Ryan	Biomedical Scientist Team Leader	NHS Lothian
Sarah Smith	Director of Newborn Screening	NHS GG&C
Tara Tchehrazi	Senior Clinical Scientist	NHS GG&C
	Parent representative	
	Patient representative	

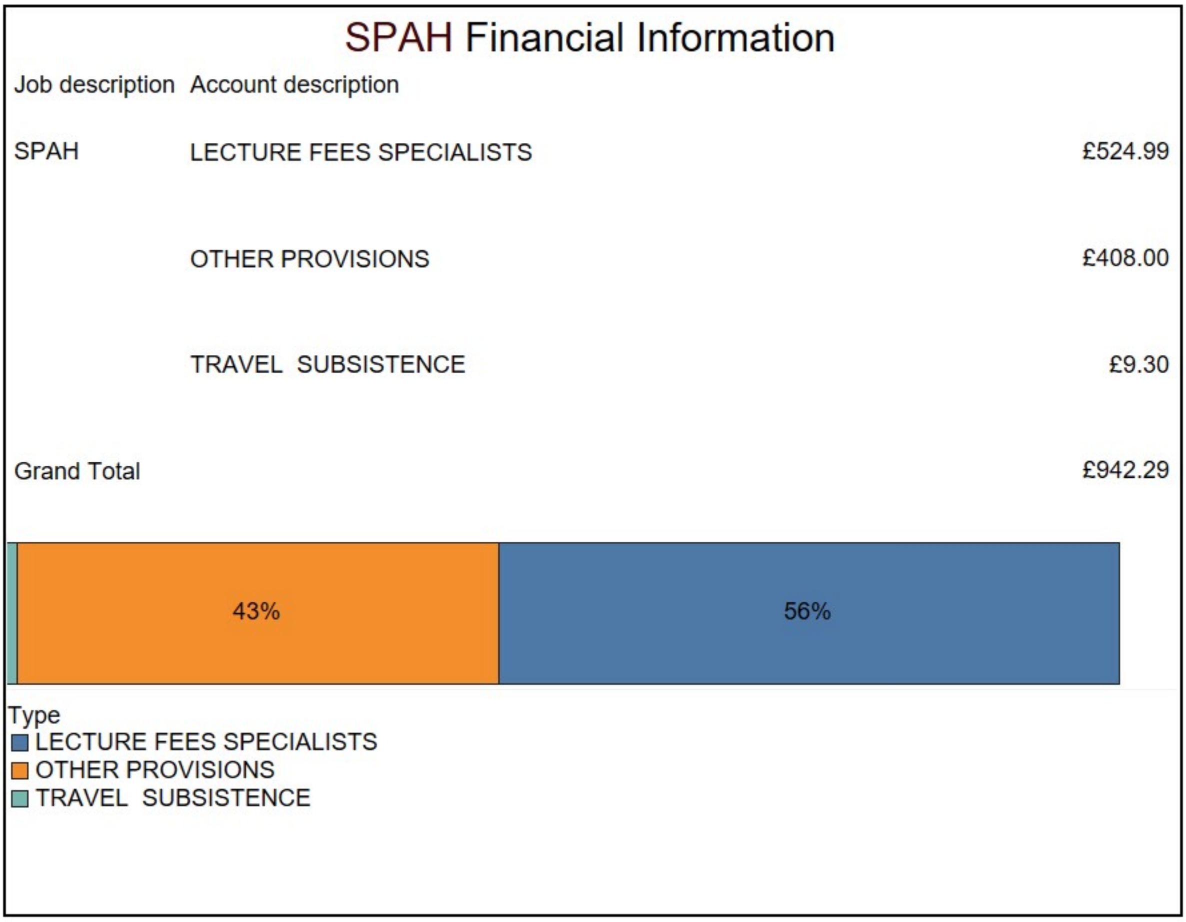
Appendix 2: Website Analytics

Full year report: from 1/4/19 > 31/3/20





Appendix 3: Finance



SPAH Financial Information

Job description	Account description	
SPAH	LECTURE FEES SPECIALISTS	£524.99
	OTHER PROVISIONS	£408.00
	TRAVEL SUBSISTENCE	£9.30
Grand Total		£942.29