

Scottish Paediatric & Adult Haemoglobinopathies Network

ANNUAL REPORT 2018/19

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1. Executive Summary

Significant progress has been achieved by SPAH in 2018/19 towards its workplan objectives.

Measuring performance has once again been a major objective for the network during 2018/19. For the second year the network has collected outcomes against all six KPIs. The network continues to undertake gap analysis of the demographic and condition information on the Clinical Audit System (CAS) which is repeated quarterly. A data “quick guide” was developed along with audit forms for use in clinic to assist clinicians to capture KPI data. A new KPI was endorsed and trialled during the reporting period, which will allow the network to audit that all patients with Thalassaemia or Sickle Cell disease are offered an annual review.

Education and information remain a priority for the network, with the aim to continue to build a range of resources for both professionals and other stakeholders. The Nursing Sub-Group was reconvened in 2018 and are leading on the review and development of patient information as well as being involved in a Nursing Education Event, which took place on 11 March 2019. SPAH continues to support multidisciplinary meetings where, in addition to case presentations with learning points, specialist peer support was provided in individual cases of ongoing treatment of patients.

The network successfully hosted a patient and family event on 22 September 2018. The event was attended by 59 people and the network took the opportunity to run a “World Cafe” to capture patient/carer views, which was well received. Feedback was collated and considered by the Steering Group for incorporation into the network’s future workplans.

A project was undertaken to gain feedback regarding experiences of using the Scottish Ambulance Service during a sickle cell crisis with responses collated from 25 parents/carers and shared with the Scottish Ambulance Service. Work will continue with the Scottish Ambulance Service to take forward an improvement project using the collated information.

SPAH were invited to present at the Rare Disease Day on 5 March 2019 at the Scottish Parliament. This was a great opportunity for the Lead Clinician to promote the ongoing work of the network and to highlight the work done to improve the lives of those living with sickle cell. The network’s patient and parent representatives provided first hand perspectives of living with or having a child with sickle cell.

Key priorities for the coming year will focus on education, engagement and quality.

- A number of education events are planned including a laboratories education event in Autumn 2019 and a SpR Education Day in Spring 2020.
- The network will also continue to engage with key stakeholders, particularly non-haematology health professionals and other non-medical professionals such as schools to develop and signpost them to online education resources.
- Further work will be undertaken to review and develop clinical guidance on the management of patients.
- A Quality Strategy will be developed outline the network’s approach for improving quality in haemoglobinopathy services.

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 2018/19

National networks have agreed core objectives that reflect the Scottish Government's expectations for managed clinical networks, as described in CEL (2012) 29¹. 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 2018/19.

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.

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, Michael Cairns.

The network has a Service Agreement with NHS NSS in place for 2017-2020.

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 list of SPAH Steering Group members is included in **Appendix 1**.

3.2. Service Development and Delivery Guidelines

The network has a timetable for the review and development of guidelines and currently has 24 guidelines available to staff involved in providing care for patients with haemoglobinopathies. Seven guidelines were due for review during 2018/19 and five have been updated and are available on the website. The remainder are nearing completion.

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

- Paediatric guideline – Acute abdominal pain in children with Sickle Cell disease
- Paediatric guideline – Iron overload and chelation therapy
- Paediatric guideline – Painful Sickle Cell Crisis (management)
- Paediatric guideline – Thalassaemia chronic transfusion
- Adult guideline – Stroke and other CNS complications

The Hydroxycarbamide Guideline, while not on the timetable for review, was updated in response to changes in the UK Guidelines.

Seven new guidelines have been proposed for development and two are complete. Progress is underway for the development of the other five.

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

Information materials

The Nursing Sub-Group was reconvened in 2018 and is leading on the review and development of patient information. Twelve leaflets are due for review and progress is underway. Two new leaflets are under development.

3.3. Stakeholder Communication and Engagement

Communication Strategy

The network developed a communication strategy following feedback from stakeholders at the patient and families event and the wider membership. The strategy was endorsed at the Steering Group meeting on 1 March 2019 and is available on the SPAH website: <https://www.spah.scot.nhs.uk/publications/>.

Website

The website has been regularly updated and is a valuable source of information for patients and professionals alike. An up to date Service Map is available. Further development will take place during 2019/2020 to update and review the content. Website analytics are available in **Appendix 2**. This shows a general upward trend in user numbers over the year.

Newsletter

The network issued a newsletter in December 2018 which included updates on the patient and families event, the reconvened nursing sub-group, guidelines, data outcomes, quality improvement projects and MDT meetings. Going forward the network plans to issue two newsletters per year.

Patient and Families Event

The Network hosted a successful Patient and Families Event on 22 September at the Edinburgh International Climbing Arena. The event was well attended with 14 families / 58 delegates. The day was a combination of education for parents/carers and young people, with fun activities for the children who enjoyed various climbing experiences as well as an arts & crafts session.

Presentations delivered on the day included:

- Update on SPAH Network activities.
- Treatment update from Sickle Cell Society.
- The Hope Project - (Support group run by patients and families for patients and families living with Sickle Cell disease)
- Lothian Self Management Programme (workshops for young people with chronic health conditions which focus on increasing mental and physical well-being)

The network took the opportunity to run a “World Cafe” to capture patient/carer views and feedback on the following areas:

- **Patient Information Leaflets** Aim: review current information leaflets and identify further information which would be helpful for patients/carers.
- **Communications** Aim: develop a strategy in partnership with patients that sets out a variety of engagement methods.
- **Patient Experience/Priorities** Aim: obtain patient & parent experience/feedback and how priorities identified will be integrated into the Network's workplan.

The sessions were well received and patients/parents feedback was collated along with event evaluation for consideration by the Steering Group for incorporation into the Network's future workplans. Three key messages from the families event:

1. Suggested requirement to improve knowledge of some Scottish Ambulance Service, General Practitioner and Accident and Emergency staff in relation to haemoglobinopathy conditions.
2. Welcomed being able to contribute to leaflet development.
3. Suggested reviewing information available to schools

Rare Diseases Event

It was a privilege for the network to be invited to present at the Rare Disease Day on 5 March 2019 at the Scottish Parliament. This was a great opportunity for the Network Lead Clinician to promote the ongoing work of the network and to highlight the work done to improve the lives of those living with sickle cell. The network's patient and parent representatives provided first hand perspectives of living with or having a child with sickle cell.



Christine Membi, The Hope Project (Acknowledgement to Claire Tennant Photography)

3.4. Education

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. 9 cases were discussed at these meetings and the network will undertake an evaluation of the MDT meetings during 2019/20.

Learning Needs Analysis (LNA)

A questionnaire was developed and issued to the nursing sub-group and A&E staff to inform future education events. An education strategy will be developed during 2019/20.

Specialist Nurses Meeting

The nursing sub-group members took the opportunity to have a short education discussion at the end of their meeting on Monday 11 March 2019 when they discussed the implications of the new hydroxycarbamide guidelines. The changes to the guideline will result in increased numbers of adult and paediatric patients being on hydroxycarbamide resulting in additional nursing time for education and monitoring. The new guidance, does, however, allow for less intensive monitoring.

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)

A project was undertaken to gain feedback regarding experiences of using the Scottish Ambulance Service during a sickle cell crisis with responses collated from 25 parents/carers and shared with the Scottish Ambulance Service. Work will continue with the Scottish Ambulance Service to take forward an improvement project using the feedback collected.

Reporting Against SPAH Key Performance Indicators

The Clinical Audit System (CAS) continues to be the national register for SPAH. There are a total of **229** active follow-up patients currently registered on CAS. The largest group is patients with Sickle Cell Disease, with the distribution across Scotland shown in the table below.

Conditions			
Treatment Centre (group)	SICKLE CELL DISEASE	THALASSAEMIA INTERMEDIA	THALASSAEMIA MAJOR
FORTH VALLEY	<5		
GG&C	103	11	11
GRAMPIAN	31	6	<5
LOTHIAN	36	<5	7
TAYSIDE	12	<5	5
Grand Total	184	21	24

The network has been working with the Information Management Service to move to the new “opt in” process for CAS to comply with General Data Protection Regulations (GDPR) Data Protection Action 2018.

Patient/family response rates to date have been increasing with **59%** of patients/ carers now having provided formal consent.

The network has continued to make progress in measuring performance against agreed performance indicators during 2018/19. The Audit Sub-Group continues to gather data on six Key Performance Indicators (KPIs). A data “quick guide” has been developed for the SPAH CAS users and three audit forms have been developed for use in clinic.

The Audit Sub-Group also approved a new KPI: **“100% of patients with Thalassaemia or Sickle Cell disease should be offered an annual review”**. Data for this will be collected for reporting in April 2020.

The network has experienced unforeseen delays in being able to report outcomes against the agreed timetable for the 2018/19 Quality Indicators due to technical problems with the reports produced from the Clinical Audit System. This issue has now been resolved and the data will be collated and analysed for

review by the audit sub-group at their meeting on 11 September 2019. Data for 2018/19 will be provided for the mid-year report in October 2019.

3.6. Value

During 2018/19 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 (although, as laid out in section 3.5, technical difficulties prevented the network from reporting on the KPIs on this occasion).
- 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. In particular, SPAH focussed on engagement with patients and families in 2018/19 and the views and priorities of patients and families will shape the future work programme of the network, most notably in relation to improving Scottish Ambulance Service provision for people affected by haemoglobinopathies.
- 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 Laboratories Education Event in Autumn 2019
- Organise and host a SpR Education Day in Spring 2020
- Continue to develop and review clinical protocols, guidelines and information leaflets, for both professional and patient groups
- Develop and endorse an education strategy
- Develop and endorse a quality strategy
- Undertake reporting against 7 Key Quality Indicators
- School Engagement – Leaflet Review

Risks/Issues:

- *New Data Protection Regulation* - The Network is working with the Information Management Service (IMS) to move to the new “opt in” process for CAS. There is concern as to the impact this may have on the audit programme being developed by the Network. This will be monitored in collaboration with the IMS.
- *Adult Ferriscan Service* - This service was previously available to all adult patients in Scotland at two locations; Grampian and Forth Valley. Management of Albyn Hospital (Grampian) changed and their contract with Alliance Medical (Provider) was not renewed. Alliance Medical also informed the Network that they would not be able to continue to offer the service through Forth Valley Royal Hospital. Due to these changes in the Adult Ferriscan Service the network is working to ensure that all patients continue to receive this service and do not miss out on necessary scans. SPAH is working with the Scottish Clinical Imaging Network (SCIN) to explore the feasibility of scans being provided locally in the NHS. In the meantime clinicians are using non-Ferriscan MRIs locally or can access Ferriscan at Royal Childrens Hospital, Glasgow.

5. Detailed Description of Progress in 2018/19

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	Linked Dimensions of Quality	Planned start/ end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective	Anticipated Outcome	RAGB status
2018-01	Update 10 guidelines in line with timetable for review.	1,2,3,4,5,6	31 March 2019	Y Protocols and Guidelines Sub-Group	5 out of 10 guidelines have been reviewed and available from the website. A further 3 guidelines were reviewed in March 2019 and awaiting sign off in April 2019	A suite of evidence based guidelines will ensure high quality haemoglobinopathy care throughout Scotland.	G
2018-02	Develop 7 new guidelines as agreed by the SPAH Protocols and Guidelines Sub-Group following recommendations from the West Midlands Quality Review Report.	1,2,3,4,5,6	31 March 2019	Y Protocols and Guidelines Sub-Group	Paediatric Thalassaemia Endocrine guideline completed and available from the website. Paediatric Transplant guideline completed in March and awaiting sign off by April, 2019. Progress underway to develop the following guidelines: <u>Paediatric</u> • Chronic Transcranial Doppler Protocol <u>Adult</u> • Acute Anaemia	A suite of evidence based guidelines will ensure high quality haemoglobinopathy care throughout Scotland.	G

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Objective Number	SMART Objective	Linked Dimensions of Quality	Planned start/ end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective	Anticipated Outcome	RAGB status
					<ul style="list-style-type: none"> • Iron Chelation • Leg Ulcers • Thalassaemia Endocrine 		
2018-03	<p>a) Reconvene nursing sub-group to lead on review and development of patient leaflets.</p> <p>b) Facilitate a session at the family day to identify other information which would be helpful for patients/carers.</p>	1	31 March 2019	Y Nursing Sub-Group	<p>a) Nursing Sub-Group took place on 17 August and the meeting agreed a plan for reviewing the leaflets currently available on the website.</p> <p>b) Feedback from session held at family day was discussed at Nursing sub-group on 11 March and list of leaflets for development finalised.</p>	Patients and their families/carers have access to good quality, up to date information to support them in living with their condition.	G
2018-04	Conduct a learning needs analysis (LNA) to inform development of Network's education strategy.	1, 2, 3, 4	31 March 2019	Y Steering Group	<p>LNA issued to Nursing sub-group for completion to inform their education event. Feedback will also be used to update LNA prior to circulation to other groups.</p> <p>LNA circulated to A&E staff to inform presentation at RCEM Scottish Clinical Meeting on 14 May.</p>	Professional in Scotland will be up-skilled in their knowledge of haemoglobinopathies.	B
2018-05	Develop a strategy in partnership with patients that sets out a variety of engagement methods and how priorities identified	1, 5	31 March 2019	Y Steering Group Network Office	Feedback collated from session at family day to identify engagement and communications methods.	The Network objective priorities will be driven by patients and family members. The Network will have met key	B

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Objective Number	SMART Objective	Linked Dimensions of Quality	Planned start/ end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective	Anticipated Outcome	RAGB status
	will be integrated into Network plan. Extend service user representation to include adults.				Communication Strategy endorsed at SOCN SG meeting on 1 March 2019. Adult Representative has joined the Steering Group at meeting on 1 Mar 2019.	objectives to increase patient and family involvement. Patient and family member will input to and influence the priorities of the Network.	
2018-06	Organise and host a family event in Autumn 2018 working with parents/ carers to develop the programme.	1, 3, 4, 5	September 2018	Y Steering Group Network Office	Family event held on 22 September. Evaluation collated along with feedback from world cafe and reviewed by Steering Group. Issues raised at family event included in 2019/20 workplan.	The Network objective priorities will be driven by patients and family members. The Network will have met key objectives to increase patient and family involvement. Patient and family member will input to and influence the priorities of the Network.	B
2018-07	Deliver a programme of audit against Key Performance Indicators.	1,2,3,4,5,6	31 March 2018	Y Audit Sub-Group	At the Audit Sub-Group meeting on 26 September the group reviewed the 2017/18 KPI outcomes and endorsed the audit timetable for 2018/19 with the view to consolidate the audit of the current KPIs. A data quick guide has been developed and is available on the website. A timetable of data update reports has been implemented to highlight to clinicians data entry	Continuing programme of audit will ensure high quality haemoglobinopathy care throughout Scotland.	B

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Objective Number	SMART Objective	Linked Dimensions of Quality	Planned start/ end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective	Anticipated Outcome	RAGB status
					requirements for the KPIs. An additional KPI was agreed at the Audit Sub-Group meeting on 27 February 2019 for collection during 2019/20.		
2018-08	Continue collation of data in relation to transition including feedback on the implementation of Ready Steady Go Hello programme to capture improvement.	1, 3, 4, 5, 6	Ongoing	Y Core Team Members	Questionnaire circulated to both paediatric and adult colleagues. Project ongoing.	Service improvements progressed.	G
2018-09	Work towards achieving a complete dataset for the Newborn Screening Programme that fulfils audit requirements. In conjunction with the antenatal screening group collaborate with Public Health to support a more robust screening programme.	1, 2, 3, 4, 5, 6	31 March 2018	Y Audit Sub-Group/ Lead Clinician	Agreed that network able to facilitate links by providing data if it is required by the Antenatal Screening Group. Meeting held on 28 August with SB/MG/LC and Lynn Hutchison to discuss links with Antenatal Screening Programme.	Continuing programme of audit will ensure high quality haemoglobinopathy care throughout Scotland	B
2018-10	Explore benchmarking opportunities against the rest of the UK through collaboration with National Haemoglobinopathy Register.	1, 2, 3, 4, 5, 6	31 March 2018	Y Audit Sub-Group	At the Audit Sub-Group meeting on 26 September it was agreed it was important to consolidate the network's audit data prior to benchmarking more widely. The sub-	Continuing programme of audit will ensure high quality haemoglobinopathy care throughout Scotland	G

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Objective Number	SMART Objective	Linked Dimensions of Quality	Planned start/ end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective	Anticipated Outcome	RAGB status
					group reviewed the National Haemoglobinopathy Quality Dashboard at the meeting on 27 February 2019 and confirmed that a number of KPIs were already being collected in Scotland, however some were not suitable to be added to audit timetable. Consider benchmarking with one centre in England in the first instance.		
2018-11	Undertake project to gain feedback from parents/carers and adult patients regarding their experiences of using SAS including questionnaire and focus group.	1, 2, 3, 4, 5, 6	31 March 2018	Y Core Team Members	Questionnaire issued to patients, parents and carers to seek feedback on experiences using SAS. Report with findings discussed at meeting with SAS on 26 March 2019. Project will be developed in conjunction with SAS in 2019/20.	Enable patients and families to take an active role in the delivery of service improvements.	B

6. Proposed Work Plan for 2019/20

Objective Number	Smart Objective	Planned start/ end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective	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		Effective delivery of the SPAH network work plan to ensure continuation of progress.	
2019-02	The network will have Terms of Reference in place for the work of the Steering Group.	30 August 2019	Steering Group		There are effective governance arrangements in place.	
2019-03	The network will meet reporting requirements: - Mid-year Report - Annual Report	31/10/19 31/05/20	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]						
2019-04	Review 3 existing and develop 4 new clinical guidelines relevant to adult haemoglobinopathy services	April 2019 / March 2020	Adult Protocol/ Guideline sub group		A suite of evidence based adult guidelines will ensure high quality haemoglobinopathy care throughout Scotland.	
2019-05	Review 2 existing and develop 2 new clinical guideline relevant to paediatric haemoglobinopathy services	April 2019 / March 2020	Paediatric Protocol/ Guideline sub group			
2019-06	Review 4 existing and develop 2 new clinical pathways	July 2019 / March 2020	Joint Paediatric & Adult Protocol/ Guideline			

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Objective Number	Smart Objective	Planned start/ end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective	Anticipated Outcome	RAGB status
			sub group			
2019-07	Review 10 paediatric patient information leaflets, 4 adult patient information leaflets, and develop 4 new patients information leaflets.	April 2019 / March 2020	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		An equitable service provision for adult patients across Scotland	
3. Stakeholder Communication and Engagement <small>[linked to Quality Dimensions 1,3,4,5,6]</small>						
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 / Rosie Hynd		Collaboration with Education organisation to develop stronger links	
2019-10	Review and maintain the SPAH website to ensure it is accurate and up to date.	April 2019 / March 2020	Laura Craig		Improved engagement with both professionals and patients	
2019-11	Conduct a learning needs analysis (LNA) with the following professional groups to inform development of Network's education strategy. <ul style="list-style-type: none"> Accident & Emergency departments 	April 2019 / March 2020	Susan Baird/ Laura Craig/ Mhairi Gallacher		Professionals in Scotland will be up-skilled in their knowledge of haemoglobinopathies	

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Objective Number	Smart Objective	Planned start/ end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective	Anticipated Outcome	RAGB status
	<ul style="list-style-type: none"> Consultants in Haematology Allied Health Professionals in Haematology 					
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		Clinicians in Scotland are aware of work of SPAH.	
4. Education [linked to Quality Dimensions 1,2,3,4,5,6]						
2019-13	Develop and endorse education strategy.	30 August 2019	Mhairi Gallacher			
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		Increased knowledge in haemoglobinopathies for relevant healthcare professionals	
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		Improved knowledge in haemoglobinopathies for healthcare professionals that either reinforces existing best practice or results in changes in practice	
2019-15	By March 2020 organise and host an education event aimed at Specialist Registrars/Trainees	June 2019/ March 2020	Mhairi Gallacher/ Laura Craig		Increased knowledge in haemoglobinopathies for relevant healthcare professionals	
2019-16	Deliver education to Royal College of Emergency Medicine in line with results from LNA (as per 2019-11)	June 2019/ March 2020	Susan Baird		Increased awareness and knowledge of conditions in professionals not routinely involved in management	

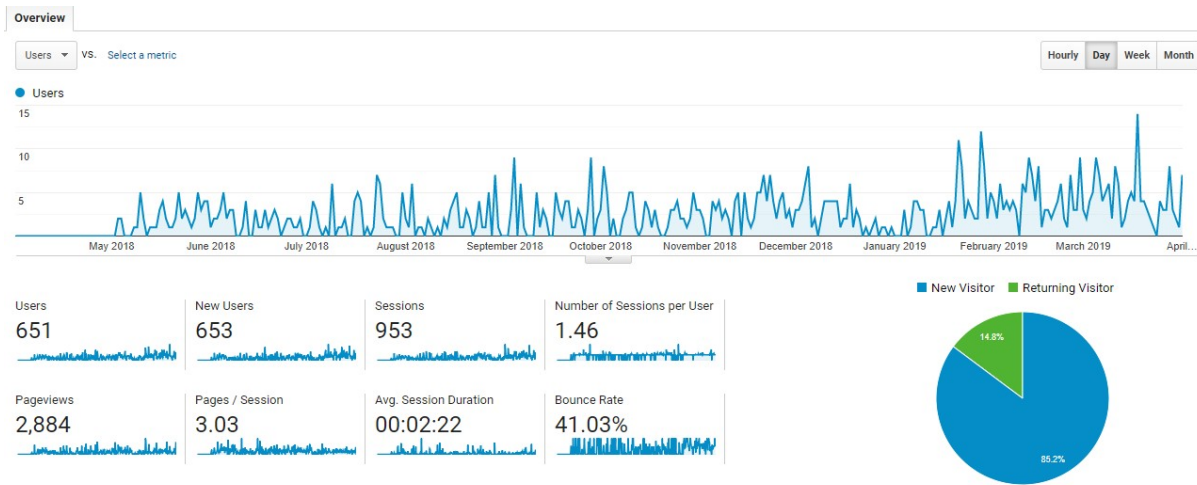
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Objective Number	Smart Objective	Planned start/ end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective	Anticipated Outcome	RAGB status
2019-17	Promote link to the PHE module to Midwives.	April 2019/ March 2020	Susan Baird/ Mhairi Gallacher			
5. Audit and Continuous Quality Improvement <small>[[linked to Quality Dimensions 1,2,3,4,5,6]]</small>						
2019-18	Data collection on new KPI - "Annual review"	April 2019/ March 2020	IT/Audit sub group		Improvements to service delivery are progressed from audit.	
2019-19	Develop a Quality Strategy to outline the network's approach for improving quality in haemoglobinopathy services.	May 2019/ November 2019	Mhairi Gallacher		Clinicians will work together to drive improvements for patient care	
2019-20	Continue delivery of a programme of audit against Key Performance Indicators	April 2019 / March 2020	IT/Audit sub group		Improvements to service delivery are progressed from audit.	
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		Service improvements progressed.	
2019-21	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		Patients will benefit from organisations working together to provide optimum care and manage risk better	
6. Value <small>[[linked to Quality Dimensions 1,2,3,4,5,6]]</small>						

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
Louise Forrest	Clinical Nurse Specialist	NHS Grampian
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

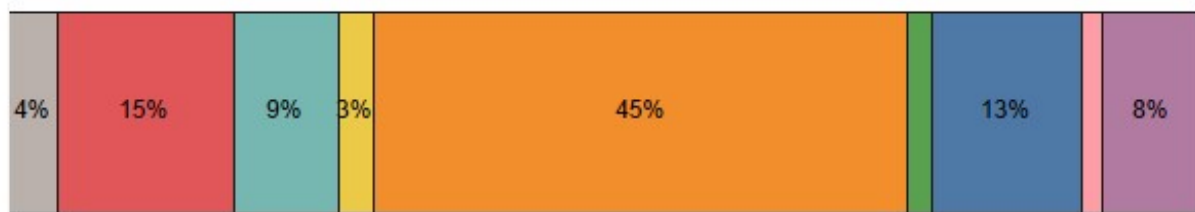


Page ?	Pageviews ?	Unique Pageviews ?	Avg. Time on Page ?	Entrances ?	Bounce Rate ?	% Exit ?	Page Value ?
	2,884 % of Total: 100.00% (2,884)	2,112 % of Total: 100.00% (2,112)	00:01:09 Avg for View: 00:01:09 (0.00%)	952 % of Total: 100.00% (952)	41.03% Avg for View: 41.03% (0.00%)	33.01% Avg for View: 33.01% (0.00%)	\$0.00 % of Total: 0.00% (\$0.00)
1. /	703 (24.38%)	530 (25.09%)	00:00:39	504 (52.94%)	23.02%	23.61%	\$0.00 (0.00%)
2. /professionals/	404 (14.01%)	290 (13.73%)	00:00:17	6 (0.63%)	16.67%	6.44%	\$0.00 (0.00%)
3. /protocolsguidelines-adult/	291 (10.09%)	214 (10.13%)	00:04:23	66 (6.93%)	24.24%	60.14%	\$0.00 (0.00%)
4. /protocolsguidelines-group-paediatric/	267 (9.26%)	148 (7.01%)	00:02:45	21 (2.21%)	33.33%	35.58%	\$0.00 (0.00%)
5. /information-leaflets/	152 (5.27%)	84 (3.98%)	00:01:27	12 (1.26%)	25.00%	29.61%	\$0.00 (0.00%)
6. /patients-and-families/	148 (5.13%)	98 (4.64%)	00:00:24	1 (0.11%)	0.00%	11.49%	\$0.00 (0.00%)
7. /genetic-counsellors/	126 (4.37%)	112 (5.30%)	00:03:33	102 (10.71%)	82.35%	79.37%	\$0.00 (0.00%)
8. /links/	120 (4.16%)	89 (4.21%)	00:01:55	39 (4.10%)	35.00%	38.33%	\$0.00 (0.00%)
9. /home-page/	71 (2.46%)	49 (2.32%)	00:00:34	4 (0.42%)	0.00%	7.04%	\$0.00 (0.00%)
10. /educational-resources/	64 (2.22%)	55 (2.60%)	00:00:14	0 (0.00%)	0.00%	14.06%	\$0.00 (0.00%)

Appendix 3: Finance

SPAH Financial Information

Job description	Account description	18/19
SPAH	EXHIBITIONS AND CONFERENCES	£224.00
	INTERNL CATERING RECHRG NPAY	£43.80
	LECTURE FEES SPECIALISTS	£340.60
	OTHER - HIRE VEHICLE	£400.00
	OTHER PRINTING STATIONERY	£57.23
	OTHER PROVISIONS	£1,207.56
	OTHER STATIONERY	£81.25
	PATIENTS TRAVEL EXPENSES	£110.70
	TRAVEL SUBSISTENCE	£235.78
Grand Total		£2,700.92



Type

- PATIENTS TRAVEL EXPE..
- OTHER STATIONERY
- LECTURE FEES SPECIALI..
- OTHER - HIRE VEHICLE
- OTHER PROVISIONS
- INTERNL CATERING REC..
- TRAVEL SUBSISTENCE
- OTHER PRINTING STATI..
- EXHIBITIONS AND CONFE..