

# SCOTTISH PAEDIATRIC & ADULT HAEMOGLOBINOPATHY NETWORK

## CONSTITUTION AND TERMS OF REFERENCE

### 1. Purpose

To facilitate clinical and other improvements in paediatric and adult haemoglobinopathy disorders through delivery of objectives set by the National Specialist Services Committee (NSSC) for NHS Boards and SGHSCD within the national commissioning process.

#### 1.1 Network Aim

To achieve the best possible clinical and other outcomes for children and adults with haemoglobinopathy disorders through better access to high quality specialist care by enabling SGHSCD policy aims of safe, effective, person centred care delivered as close to home as possible.

#### 1.2 Network Objectives

- 1.2.1 Design and ongoing development of an effective Network structure that is organised, resourced and governed to meet requirements in relation to SGHSCD Guidance on MCNs (currently CEL (2012) 29) (Annex and national commissioning performance management and reporting arrangements);
- 1.2.2 Support the design and delivery of services that are evidence based and aligned with current strategic and local and regional NHS planning and service priorities.
- 1.2.3 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 User are involved in the Network and explicitly in the design and delivery of service models and improvements.
- 1.2.4 Improved capability and capacity in haemoglobinopathy care through design and delivery of a written education strategy that reflects and meets stakeholder needs.
- 1.2.5 Effective systems and processes to facilitate and provide evidence of continuous improvement in the quality of care (CQI).
- 1.2.6 Generate better value for money in how services are delivered.

### 2. Composition

#### 2.1 Full Membership

The full membership of Scottish Paediatric & Adult Haemoglobinopathy Network shall be:

- Network Steering Group
- All staff members working within IT/Audit sub group, Multidisciplinary (MDT) group, Nurses group, adult Protocols/Guidelines group and paediatric Protocols/Guidelines group.

External Stakeholders include:

- Any stakeholder who has an interest in paediatric & adult haemoglobinopathies
- Charities/support groups
- Educational institutions
- Professional bodies

External stakeholders form part of the wider landscape for paediatric and adult haemoglobinopathies in Scotland. The work of the Scottish Paediatric & Adult Haemoglobinopathy Network may require interaction with commercial partners on specific issues. Any such interactions would be subject to separate governance arrangements as necessary.

## 2.2 Core Team

The SPAH Lead Clinician and the NNMS Programme Manager and Programme Support Officer form the network's Core Team.

## 2.3 Network Steering Group

The steering group's remit is to provide strategic direction. The steering group shall be representative of the different professional disciplines from the paediatric and adult haemoglobinopathies community and their geographical boundaries.

It will consist of:

- Lead Clinician (Chair)
- Patient / Family / Carer representation (including, where applicable, third sector organisations)
- Representatives of relevant professional groups
- Representatives of NHS Health Boards
- Representation from SNBTS
- Representation from NBS
- Representation from network Subgroups / Working Group (usually the group lead or a deputy)

*Please refer to Section 9 on Page 7 for the full Steering Group Membership*

Steering Group members who represent a Health Board or relevant healthcare profession within the network should be given protected time within their Job Plan / personal objectives to contribute to the network.

Steering Group members who are representatives are responsible for relaying information and views between their local services and/or professional group and the network Steering Group.

Steering Group membership will be reviewed regularly to ensure it is effective, appropriate and representative of the network's full range of stakeholders.

## 2.4 Subgroups / Working Groups

Network Subgroups / Working Groups will be set up as required to work on specific projects as requested by the network Steering Group. These will consist of interested parties with experience and expertise relevant to the project concerned. Any network member may volunteer or be approached to join a project subgroup.

Subgroup / Working Group members who represent a Health Board or relevant healthcare profession within the network should be given protected time within their Job Plan / personal objectives to contribute to the network.

The Paediatric and Adult Guidelines Sub-Groups will have the authority to develop, review and endorse guidelines. A regular update will be provided at Steering Group Meetings.

## **3. Appointments**

### **3.1 Network Lead Clinician**

The role of the Lead Clinician is to provide clinical expertise and leadership in the ongoing development of the network and be accountable, on behalf of the Steering Group, for network performance in meeting agreed aims and objectives.

The Lead Clinician shall be appointed for an initial period of up to three years. The Lead Clinician can remain in post for an additional year after this period. Any extension would need to be formally proposed to NSD as commissioners of the network and be supported by both the network Steering Group and the commissioners.

The National Network Management Service (NNMS) in National Services Scotland will recruit the Lead Clinician on behalf of and for SPAH.

### **3.2 Network Management**

Network management is provided to the network by the National Network Management service (NNMS) through National Services Scotland. The NNMS Programme Manager and Programme Support Officer will support the delivery of the workplan for SPAH, working flexibly to accommodate the fluctuating needs of network activity.

### **3.3 Chair**

If the network opts to have an independent Steering Group Chair, a Chair will be nominated from the network membership and associated services. They will be appointed for a period of up to three years with overlap with the Lead Clinician to help facilitate effective management of meetings and strategic planning. The Chair can remain in post for an additional year after this period. Any extension would need to be formally proposed to NSD as commissioners of the network and be supported by both the network Steering Group and the commissioners.

### **3.4 Administrative Support**

Administrative support to the network will be provided by NNMS.

### **3.5 Information Management Support**

Information management support to the network will be provided by the Information Management Service (IMS) in NNMS. A named Data Analyst will be identified by IMS to support the network.

## **4. Meetings**

### **4.1 Network Steering Group Meetings**

The Steering Group shall meet on at least three occasions each year or more if required.

Steering Group meetings will be timetabled well in advance, usually with an annual schedule of meetings set at the start of the year.

In the absence of an identified network Chair, meetings will be chaired by an appropriate network member, usually the Lead Clinician.

Steering Group members are required to attend the meetings or be represented by a deputy. Tele or videoconferencing will be arranged, where possible, if required. Any Steering Group member who misses three meetings in a year and does not send a deputy will be asked to consider their continued membership.

Meetings will only go ahead if there is a quorum of members in attendance. A meeting can be considered quorate if at least a third of members are present (or represented by a deputy) and those present provide sufficiently broad representation of the network's stakeholders.

Other representatives may be invited to Steering Group meetings as observers only.

The agenda and associated papers shall be circulated by email to the Steering Group members five working days in advance of the meeting date.

Meeting minutes detailing decisions and work to be carried out as a result of the meeting will be produced in line with agreed NNMS standards. They will be circulated by e-mail to the network steering group in draft form and will be ratified at the subsequent Steering Group meeting. Draft minutes will be circulated to Steering Group members no later than three weeks after the meeting. This does not preclude Steering Group communication detailing the progress of current initiatives between meetings.

The NNMS will provide administrative support to the Steering Group meetings.

## **4.2 Subgroup / Working Group Meetings**

Network Subgroups / Working Groups shall have a designated lead responsible for coordinating the group's work and to feed back to the Steering Group.

Subgroups / Working Groups shall determine the frequency of meetings according to the objectives and timescale of the work to be undertaken.

The Steering Group shall estimate the likely time commitment of group members in advance.

Meetings shall be timetabled in advance to enable coordinated reporting to the network Steering Group meetings. It is expected that Subgroup / Working Group chairs be present at meetings to provide feedback on progress and highlight any issues. If unavailable, they should send a deputy or provide a written update.

The agenda and associated papers shall be circulated by email to members of the Subgroup / Working Group five working days in advance of the meeting date.

## **5. Accountability**

SPAH is formed of a number of relevant experts who will influence and enable health boards and individual services/organisations/charities/support groups/professional bodies to work collaboratively on issues to benefit patient care and improve efficiency of service provision. SPAH is accountable to the Scottish Government Health and Social Care Directorate (SGHSCD) through National Services Division, for delivery of the network's objectives, and should report any delivery issues through National Services Division to seek appropriate support within national commissioning governance..

## 5.1 The Core Team

The Core Team (Lead Clinician, Programme Manager and Programme Support Officer) will:

- Work collaboratively with network members to develop appropriate draft work plans for consideration and endorsement by the Steering Group and Commissioners.
- Review all work of add network name here, direct work plans, and ensure reporting to the network Steering Group.
- Lead the Steering Group and work collaboratively with Steering Group members.
- Support the work of the network Steering Group and project subgroups/ working groups.
- Coordinate effective communication between its stakeholders, including between the network Steering Group and Subgroups / Working Groups.
- Provide leadership to the network to be able to articulate network responses to national policy, and to develop national quality standards, guidelines and pathways.
- Prepare an annual report which will be presented to National Services Division (National Services Scotland). NNMS has strategic oversight over all NMCNs on behalf of the SGHSCD.

## 5.2 Network Steering Group

The Network Steering Group representatives shall:

- Represent their NHS Board or stakeholder group on the network.
- Communicate the work of SPAH with other members of their NHS Board / the stakeholder group they represent.
- Be responsible for agreeing the work plan and overseeing its delivery, against agreed timescales.
- Engage with the work of the network and respond to consultation exercises, surveys and audits.
- Participate in consensus decisions.

Individual representatives will have equal say in the decisions of the Steering Group. Decisions will be based upon the consensus of Steering Group members. The chair's role will be to facilitate a group consensus so that a decision can be made.

## 5.3 Subgroups/Working Groups

Subgroups/Working Groups shall:

- Be accountable for delivery of objectives set by the Steering Group within the timescale agreed.
- Monitor and report on their progress to the Network Steering Group.
- Raise any issues with the Core Team.

## 5.4 Clinical Governance

SPAH has a responsibility to report any potential areas of risk to patient safety, to the NHS Board(s) in which the risk is identified. A confidential record of risks and actions taken will be maintained. Responsibility for acting on the risk remains with the NHS Boards.

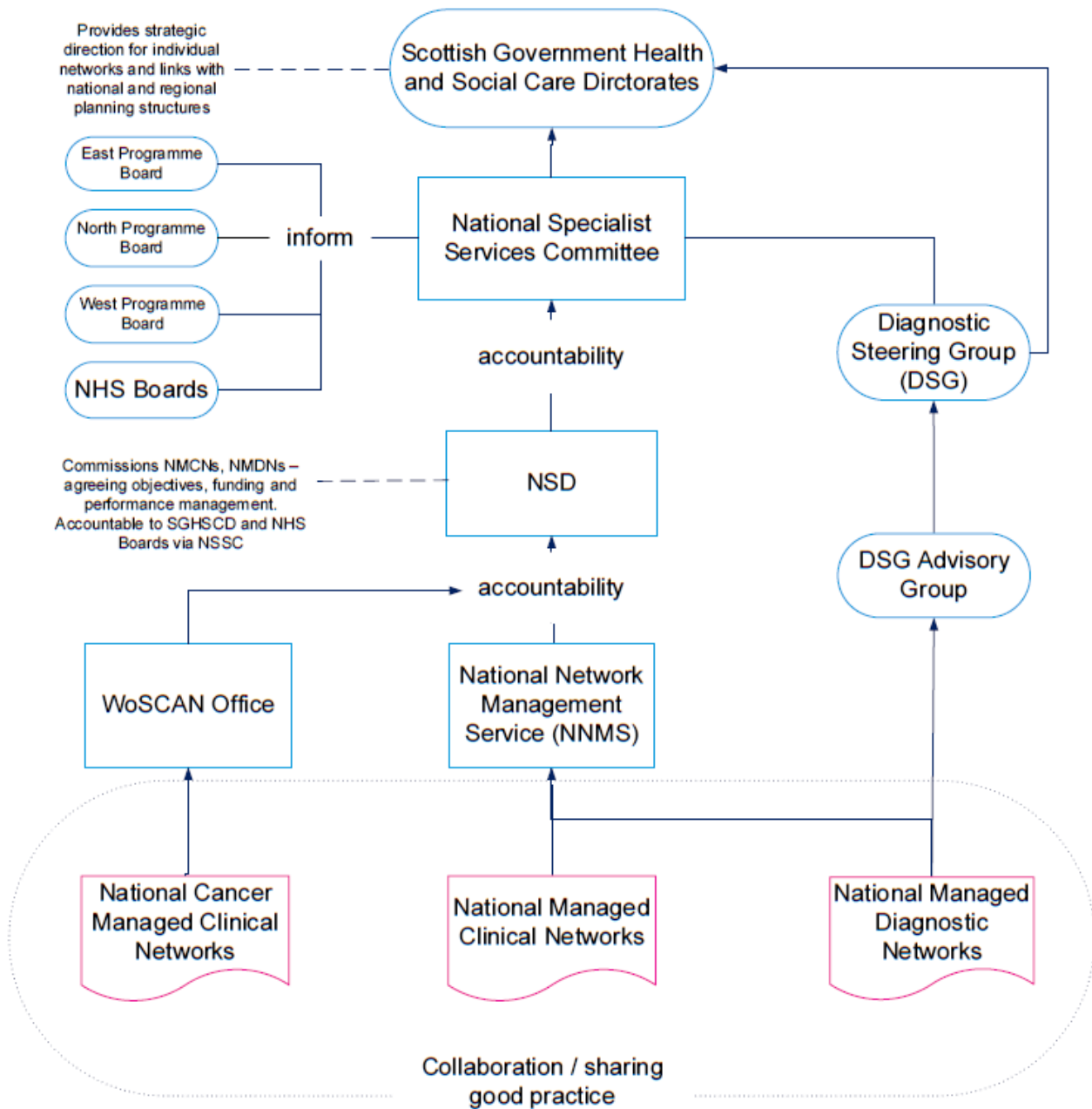
## 6. Expenses

Travel expenses are available to non-NHS Board employees, and are paid in line with NSS' travel and subsistence rates. Contact [nss.spah@nhs.net](mailto:nss.spah@nhs.net) for details.

# 7. Patient Confidentiality

Patient confidentiality must be maintained at all times, in line with NHS Scotland policy. Where papers are marked as 'Confidential' they should not be circulated outwith the Steering Group.

## 8. Structural arrangements: National Commissioning Governance for National Networks (NSD610-001.05)



## 9. SPAH Steering Group Representation

Name	Organisation	Designation/ Network Role
Ruth Allen	NHS Greater Glasgow & Clyde	Consultant Paediatric Radiologist
Susan Baird	NHS Lothian	Consultant Paediatric Haematologist
Ruth Bissell	NHS Greater Glasgow & Clyde	Haematology Paediatric Nurse Specialist
Vicky Brace	NHS Greater Glasgow & Clyde	Consultant Obstetrician
Kim Campbell	NHS Greater Glasgow & Clyde	Senior Clinical Scientist – Newborn Screening
Srinivasa Dasari	NHS Lanarkshire	Consultant Haematologist
Lyn Hutchison	NHS National Services Scotland	Senior Programme Manager
Alice Klauser	NHS Lothian	Consultant Haematologist
Mark Longmuir	NHS GGC	Consultant Genetic Counsellor
Louisa McIlwaine	NHS Greater Glasgow & Clyde	Consultant Haematologist/ / Lead Clinician
David McLaughlin	NHS Tayside	Consultant Haematologist
Nicole Pridee	Scottish National Blood Transfusion Service	Consultant in Transfusion Medicine
Lucy Paterson	NHS Lothian	Clinical Nurse Specialist
Fernando Pinto	NHS Greater Glasgow & Clyde	Consultant Paediatric Haematologist
Beverley Robertson	NHS Grampian	Consultant Haematologist
Bernadette Watters	NHS Greater Glasgow & Clyde	Haemoglobinopathy Clinical Nurse Specialist
		Patient representative
		Parent representative

### National Network Members

Mhairi Gallacher	National Services Division	Programme Manager
Karyn Robertson	National Services Division	Senior Programme Manager
Linda Watson	National Services Division	Programme Support Officer